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# **The experiences of patients living and dying with advanced heart failure in Kenya: a qualitative serial interview study**

**Kellen Njeri Kimani**



Doctor of Philosophy - The University of Edinburgh - 2017

## Declaration page

I declare that:

- a) this thesis has been composed solely by myself
  - b) the work presented in this thesis has not been submitted, in whole or in part, in any previous application for a degree.
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Kellen Njeri Kimani

5<sup>th</sup> August 2017

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Date

# **Abstract**

## **Background**

The number of people in Sub-Saharan Africa dying of heart failure is increasing. However, little is known about their experiences and needs. In Kenya, palliative care services are available for some people with cancer and HIV/AIDS, but these services may not be configured to meet the needs of patients dying with heart failure.

## **Aims and objectives**

This study aimed to explore the experiences of patients living and dying with heart failure in Kenya. Specifically, it sought to understand how patients describe their illness experience, their experience of receiving treatment and care, and their perspectives on how their care could be improved.

## **Methods**

Twenty patients admitted and diagnosed with advanced heart failure were purposively recruited from a rural district hospital. Serial in-depth interviews were conducted with patients at 0, 3 and 6 months after recruitment. Bereavement interviews were carried out with carers. All interviews were conducted and recorded in the local language of Kiswahili, transcribed into English and analysed thematically with the assistance of Nvivo software.

## **Results**

Forty-four interviews were conducted. Three significant phases were identified in patients' experience (i) coming to a diagnosis, (ii) living with heart failure and (iii) dying with heart failure. Before receiving the diagnosis of heart failure, many patients were mistakenly misdiagnosed with common

serious infectious conditions such as pneumonia, tuberculosis, and malaria. Once treatment commenced and physical symptoms abated, many patients were hopeful of a full recovery, unaware that there would be a progressive deterioration in their health. Social relationships were a source of encouragement but were strained by the accumulating cost of care. Patients particularly those who were younger, felt anxious or depressed when symptoms failed to improve with treatment. Uncertainty was prevalent and underlay patients' experiences from the time of diagnosis to the end of life. Very few patients spoke about the possibility of death believing that life and death are in the hand of God. Majority of patients had poor understanding of their illness and expressed a need for more information and better communication with health professionals.

## **Conclusion**

Patients with advanced heart failure in Kenya have significant unmet physical, psychological, social, spiritual, financial, and information needs. Patients' narratives pointed to how they could benefit from a holistic approach aimed at catering for their multidimensional wellbeing. There is need to improve patients access to information and support better communication with health professionals. Chronic disease management aimed at (i) early identification of patients (ii) improving treatment and care guidelines and (iii) promoting primary and secondary prevention to identify, treat and control common risk factors for heart failure is needed.

## **Lay summary**

The number of people dying from heart failure in Sub-Saharan Africa is increasing. However, little is known about how they experience their illness and their needs. Heart failure occurs when the heart is struggling to pump blood around the body and the person becomes breathless, their legs swell, and they cannot walk far. In Kenya, palliative care services are available to help people with cancer and HIV/AIDS. However, these services may not support the needs of people dying of heart failure.

We conducted this study to find out what is it like for people with heart failure to live with their illness. We also wanted to understand their experience with treatment and how they would like their care improved.

To answer these questions, we asked patients admitted to a rural district hospital with a heart failure diagnosis whether they would like to take part in this study. We planned to conduct three interviews with each patient over a period of six months. We also interviewed carers if a patient got worse or died and could no longer take part in the study. Interviews were conducted in Kiswahili (local language in Kenya) and then written in English. Quotes from the interviews were analysed with help from a computer data analysis software (Nvivo).

In total, 44 interviews were conducted. We found three important phases in patients' experience: (i) coming to a diagnosis, (ii) living with heart failure and (iii) dying with heart failure. Before receiving the diagnosis of heart failure, many patients were mistakenly misdiagnosed with common conditions such as pneumonia, tuberculosis, or malaria. Once treatment started and symptoms improved, patients were hopeful for a full recovery and remained unaware that their health was deteriorating. Family and

friends encouraged patients but relationships were strained by the increasing cost of care. Patients, particularly those who were younger, felt anxious or depressed when symptoms failed to improve with treatment. Very few patients spoke about death because they believed life and death are in the hand of God. Many patients did not understand their illness and wanted more information and better communication with their health care provider.

In conclusion, this study shows that patients with heart failure in Kenya have multiple needs. In addition to physical problems, patients are anxious, they worry about the future, and at times question God. They also have little understanding of their illness. Patients' stories show that a service, which can take care of their multiple needs, might improve their wellbeing. There is need to improve patients' access to medicines and information and support better communication between them and health professionals. Care aimed at identifying patients earlier and promoting prevention of heart failure is needed.

## Acknowledgements

I would like to express my sincere appreciation to my supervisors Dr. Liz Grant and Prof Scott Murray for their guidance throughout this project. I am grateful for their mentorship, constant encouragement, patience and their faith in me. Many thanks also to Dr. Kirsty Boyd for her support, generosity and valuable input.

Special and heartfelt gratitude goes to patients and carers who volunteered to take part in this study. Their enthusiasm in the midst of challenging life circumstances is a testament to the resilience of the human spirit. I am grateful for the opportunity and privilege to share their experiences.

My deep appreciation goes to my PhD peers for their comradeship. Their support during high and low moments was a source of comfort. Special thanks to my colleagues at the Primary Palliative Care Research Group for their practical insights and helpful comments.

My sincere gratitude to the many friends who have made my time in Edinburgh enjoyable. I am grateful for their kindness and hospitality. Special thanks to the 'All Nations Family' for sharing their faith and for the wonderful memories made.

And to my family: Dad, Mum, my brother Njoroge and sister Wanjiku. I am deeply grateful for their support, for always being there for me and for cheering me on. I dedicate this thesis to them.



## **Abbreviations**

AIDS	Acquired Immune Deficiency Syndrome
APCA	African Palliative Care Association
COPD	Chronic Obstructive Pulmonary Disorder
CVDs	Cardiovascular Diseases
DCM	Dilated Cardiomyopathy
DM	Diabetes Mellitus
HHD	Hypertensive heart disease
HIV	Human Immunodeficiency Virus
IHD	Ischaemic Heart Disease
KEHPCA	Kenya Hospice and Palliative Care Association
NCDs	Non-communicable Diseases
NHIF	National Hospital Insurance Fund
NYHA	New York Heart Association
RHD	Rheumatic Heart Disease
SSA	Sub-Saharan Africa
THET	Tropical Health Education Trust
WHA	World Health Assembly
WHO	World Health Organisation

# **Chapter overview**

## **Chapter 1: Introduction**

This chapter outlines background information informing this study. It begins by examining the burden of heart failure in Sub-Saharan Africa and follows with an overview of international research exploring the experiences of patients living and dying with heart failure including their care. This chapter concludes with a description of the research setting.

## **Chapter 2: Literature review**

This chapter offers a critical review of empirical and theoretical literature that has provided the foundation for the justification of this research. The first section presents a scoping review of heart failure in Sub-Saharan Africa. The second section outlines sociological perspectives on living with chronic illness and details African perspectives on health and illness. This chapter concludes with this study's research aim and questions.

## **Chapter 3: Conducting the research**

This chapter describes how this research was carried out. It begins with an overview of methodologies and methods that directed this study. This section is followed by an outline of procedures for participant recruitment and data management, and consideration of ethical issues in conducting this work. This chapter concludes with a reflexivity section reviewing my personal subjectivities and how they influenced the conduct and interpretation of this research.

## **Chapter 4: Participants and Interviews**

This chapter summarizes the clinical and sociodemographic characteristics of study participants and describes the interviews conducted for this research.

## **Chapter 5-7: Patients' experience**

This chapter presents findings of patients' perspectives of living and dying with heart failure. Chapter 5 outlines the experience of heart failure as described by patients; Chapter 6 presents their experience with care and Chapter 7 details their perspectives on how their care can be improved. Each chapter concludes with a discussion of findings which is an explanatory account that brings together participants' descriptions and observations inferred by the researcher. This discussion incorporates findings from previous empirical and theoretical work and acknowledges the influence of the local context where this study was conducted.

## **Chapter 8: Integration of research findings, recommendations for practice, policy and future research**

This chapter integrates the findings presented in Chapter 5-7 in three key themes: transition from health to illness, uncertainty of living and dying with heart failure and lack of information and poor communication with health professionals. This section is followed by a discussion of the strengths and limitations of this study, recommendations for practice and policy, and implications for future research.

## **Chapter 9: Reflection of conducting the research in Kenya**

This chapter narrates the challenges and opportunities of conducting a longitudinal qualitative study in Kenya.

## **Note on style and language**

This thesis is written with the intention of sharing its findings with readers of cardiology, palliative care, and public health academic journals. In doing so, I have written most of this thesis in the third person to appeal to this target audience and to support my critical realist ontological position that assumes an independent external reality. However, I acknowledge that qualitative inquiry is an interpretive science in which a researcher becomes actively involved in the research process, and writing in the first person allows the researcher to account for personal experiences, beliefs, and views that might introduce bias into a research project. To account for my subjectivity, which may have influenced this research, I have included a section on reflexivity in Chapter 3 to support rigour and transparency.

### **Definition of key terms**

**Participants:** this refers to patients and carers who agreed to take part in this study.

**Patients:** people diagnosed with advanced heart failure who fit the inclusion criteria and agreed to participate.

**Carer:** a person chosen by a patient as ‘the person who takes care of them’ who fit the inclusion criteria and agreed to take part.

**Health professional(s):** this refers to people involved in the diagnosis and treatment of human illness. This includes doctors, nurses, and pharmacists. This definition is guided by the international standard classification of occupations (ILO, 2013). In the Kenyan context, this also includes clinical

officers who are trained to work independently or under the supervision of other health professionals.

**Health facility:** hospitals or clinics providing health services.

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# **Chapter 1 : Introduction**

This chapter provides background information to place this study in the context of Sub-Saharan Africa. It begins with an overview of the burden of heart failure and follows with a description of patients' experiences of living and dying with heart failure. This chapter concludes with a description of the setting in which this research was conducted.

## **1.1 Heart failure in Sub-Saharan Africa**

By 2030, it is projected that non-communicable diseases (NCDs) will overtake communicable diseases as the leading cause of death in SSA (SSA) (Dalal et al., 2011). This change in disease pattern is a result of better communicable disease control, which has improved survival into adulthood. People in SSA are now living longer to experience accumulative exposure to NCD risk factors. These risk factors include the adoption of unsafe habits (smoking and alcohol use), unhealthy diets, and physical inactivity (WHO, 2014b ; Beaglehole and Yach, 2003).

For many decades, heart failure has been recognized as a significant problem for SSA. Early case studies from West Africa (Bedford and Konstam, 1946) reveal poor outcomes for people with heart failure. However, overwhelming challenges from infectious diseases and maternal and child health conditions has meant more attention has been given to these conditions at the expense of NCDs (Dalal et al., 2011).

In recent years, research on heart failure in SSA has been growing reflecting an increasing and significant disease burden (Damasceno et al., 2012).

Preliminary hospital-based surveys such as 'The Sub-Saharan Africa Survey

of Heart Failure' (THESUS-HF) (Damasceno et al., 2007) and the 'Heart of Soweto Study' (Stewart et al., 2008a) have been conducted to determine the distribution, clinical and sociodemographic characteristics and outcomes of heart failure. The results of these studies point to a high disease burden with heart failure occurring in younger people when compared to high-income countries (Bloomfield et al., 2013 ; Stewart et al., 2008a).

While this advancement in epidemiological knowledge is welcome, it is essential to understand the experiences of patients living and dying with heart failure in SSA. This evidence base is lacking (Kimani et al., 2016a) but is crucial for tailoring services to meet patients' needs (Selman et al., 2015). In most settings in SSA, health services are structured for acute episodic care and may not be responsive to the dynamic needs of patients with chronic illnesses (Yach et al., 2004). Chronic diseases require complex interventions and coordination of services to be sustained throughout the continuum of care (Samb et al., 2010). Evidence of patients' experience is needed to determine priorities for care and develop responsive services (Lynn J, 2003).

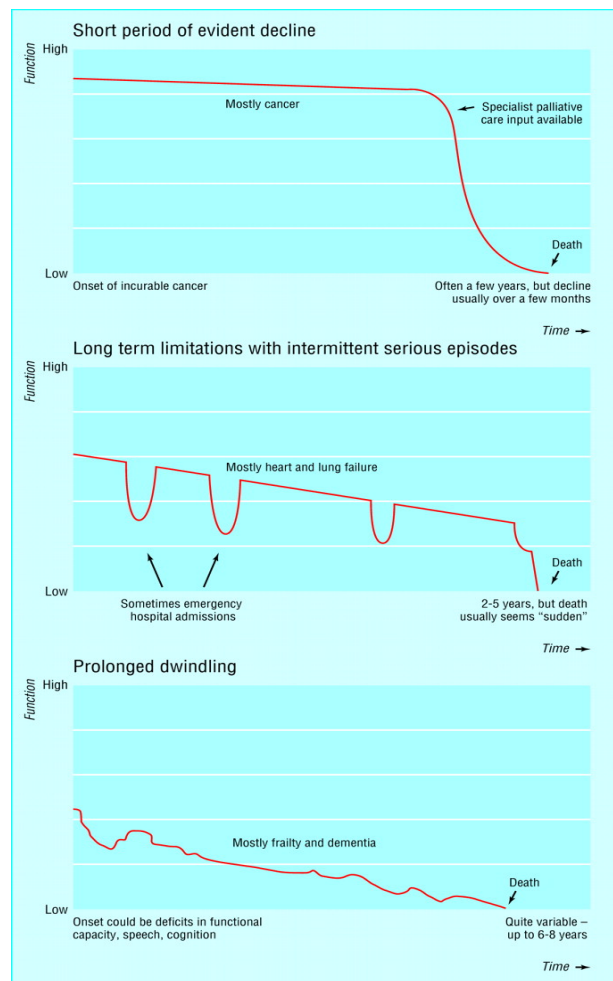
In SSA, qualitative research exploring the needs of patients at the end of life is mainly focussed on HIV/AIDS and cancer (Gysels et al., 2011). Trajectories of these illnesses may differ with that of heart failure and may not be appropriate for informing services. Selman et al. (2015) have identified a similar gap in the literature and propose that research is needed to explore the experiences and multidimensional needs of patients with heart failure. Conference abstracts indicate that this research is already underway in Uganda (Namukwaya et al., 2014) but research from other SSA countries is needed to account for differences in health systems and reflect the rich ethnic and cultural diversity of the sub-continent.

## 1.2 Heart failure trajectory

Heart failure is a complex condition in which the heart fails to sustain adequate circulation to deliver sufficient oxygen to meet the body's metabolic demand. Patients often present with signs and symptoms suggestive of fluid and salt retention, especially during acute exacerbations. Heart failure is characterised by a gradual decline in health status which is punctuated by acute exacerbations that can result in sudden death (Murray et al., 2005 ; Lynn J, 2003). Unlike the cancer trajectory with a more predictable entry into the end of life, the terminal phase of heart failure is unpredictable (Fig 1).

**Figure 1:** Illness trajectories of progressive chronic illness.

Source: Murray et al (2005)





Despite advances in medical therapy, the prognosis of heart failure remains poor. Heart failure is associated with significant symptom burden and mortality rates approaching those of cancer (Jaarsma et al., 2009). For instance, patients with heart failure and those with advanced pancreatic and lung cancer have been found to have similar physical, psychological and spiritual symptom burden (Bekelman et al., 2009 ; O'Leary et al., 2009). Furthermore, studies conducted in the United Kingdom show that 30-40% of patients with heart failure die within a year of diagnosis (Cowie et al., 2000). Heart failure has a poorer five-year survival rate of 25% when compared to bowel cancer (40%) and breast cancer (60%) in men and women respectively (Stewart et al., 2001)

Most patients with heart failure will pass through three stages: a primary stage of good performance status requiring mainly chronic disease care, a secondary phase of declining wellbeing needing supportive and palliative care, and a tertiary phase marking the last days of life. Although patients may survive acute exacerbations, death can occur suddenly and unexpectedly (Boyd et al., 2009 ; Jaarsma et al., 2009). Prognostication for heart failure is difficult, but several clinical and biochemical indicators are available to assess, to a limited degree, response to treatment and identify when a patient's health status is deteriorating. The New York Heart Association Classification system (NYHA) is a useful clinical guide to assess patient's response to treatment and identify those with deteriorating health (Jaarsma et al., 2009)(Table 1 overleaf).

**Table 1:** *New York Heart Association Classification.* Source: The Criteria Committee of the New York Heart Association (1954)

Class	Patient Symptoms
I	No limitation of physical activity: Ordinary physical activity does not cause undue breathlessness, fatigue, or palpitations.
II	Slight limitation of physical activity: Comfortable at rest but physical activity results in breathlessness, fatigue or palpitation,
III	Marked limitation of physical activity: Comfortable at rest but less than ordinary activity causes breathlessness, fatigue, or palpitations
IV	Unable to carry on any physical activity without discomfort. Symptoms of heart failure occur at rest and discomfort increases with physical activity

### 1.3 Living and dying with advanced heart failure: International Perspectives

Several qualitative studies exploring the end of life experiences of patients with heart failure have been conducted in Europe, North America and New Zealand (Low et al., 2011a). These studies show that patients face significant physical, psychosocial and spiritual problems.

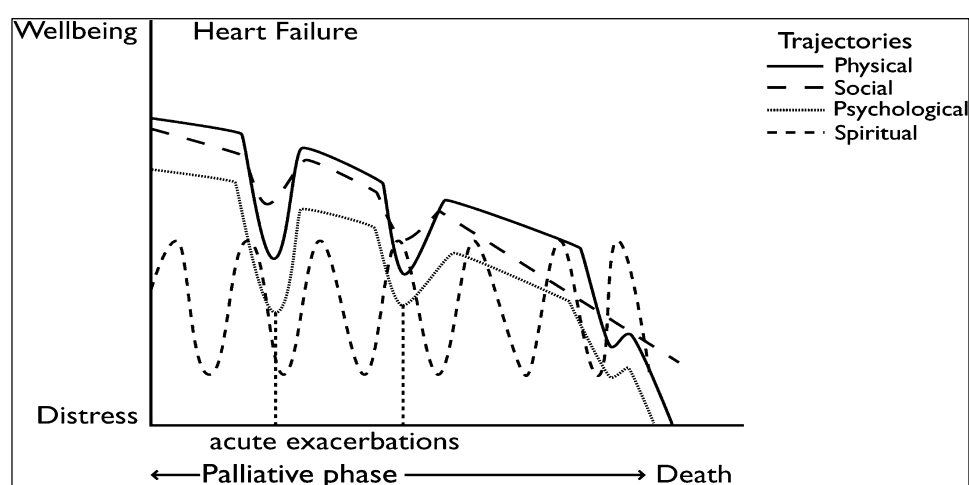
#### 1.3.1 Physical problems

Physical symptoms such as severe breathlessness, fatigue, sleep disturbance, pain, weight changes and reduced physical capacity are common in patients with heart failure (Zambroski, 2003 ; Boyd et al., 2004). Gradual deterioration in physical wellbeing is at times interrupted by periodic acute episodes, which may lead to a hospital admission. Some recovery may occur but death

can be sudden (Fig 2) (Murray et al., 2004). Worsening physical symptoms disrupt patients' daily life and may limit their engagement with previously enjoyed activities. Patients may feel as though their life is restricted which may trigger negative emotions such as anxiety and depression (Hopp et al., 2012 ; Horne and Payne, 2004).

**Figure 2:** Physical, social, psychological and spiritual decline in last year of life.

Source: Murray et al. (2007)



### 1.3.2 Psychosocial problems

Psychosocial and physical issues tend to occur hand in hand (Fig 2) (Murray et al., 2007). As physical symptoms begin to limit functional capacity, a feeling of being trapped pervades patients' lives. Patients feel less confident about taking part in activities that previously brought meaning (Dougherty et al., 2007) which leads to frustration and disappointment (Zambroski, 2003). Further physical decline means that patients may need to rely on the support of family members to complete daily tasks including self-care. Having to rely on others may cause patients to experience a loss of

independence, which may lead to further despair (Thornhill et al., 2008 ; Ryan and Farrelly, 2009). Feelings of guilt may occur when patients are unable to meet others' expectations of their physical ability. Some patients may resolve to remain independent to avoid being a burden to those who care for them which may result in further isolation (Horne and Payne, 2004).

### **1.3.3 Spiritual problems**

Spirituality refers to the way people find meaning, and how they connect with self, others and the sacred (Puchalski et al., 2009). Unlike the psychosocial and physical trajectory which tend to occur together, decline in spiritual well-being varies as patients try to come to terms with progressive loss (Fig 2) (Murray et al., 2007). The unpredictable nature of heart failure triggers feelings of uncertainty and reminds patients of the inevitability of death. A sense of loss may inspire patients to try to find meaning in their experience (Beery et al., 2002). Patients may review past events to explore possible explanations (Murray et al., 2004) or find purpose through their social relationships or spiritual beliefs (Westlake and Dracup, 2001 ; Grant et al., 2004).

## **1.4 Care for patients with advanced heart failure**

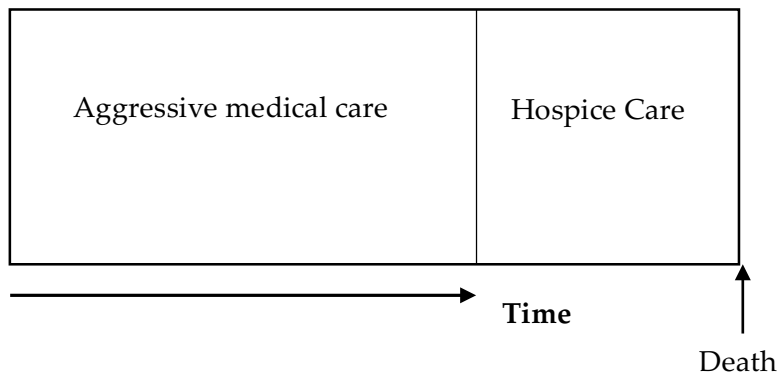
Palliative care is a holistic patient-centred approach that aims to:

*'improve the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'*

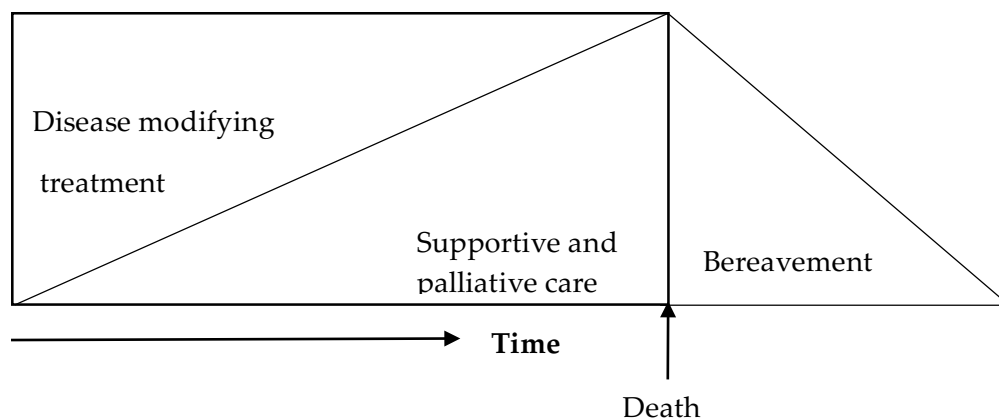
(WHO, 2004).

Palliative care recognizes dying as a natural process. It aims to support patients to cope positively and live actively as much as possible until death (WHO, 2004). Although palliative care has roots in oncology (WHO, 2004), the World Health Assembly recently recommended the integration of palliative care along the continuum of care for all disease groups including non-malignant diseases, in response to the growing global burden of NCDs. Integration aims to provide relief from avoidable suffering and provides people with comprehensive, patient-centred, equitable and dignified care at the end of life (WHA, 2014). Integration is a departure from the old approach to palliative care where care was offered after curative therapy provided no additional therapeutic benefit. A trajectory approach allows palliative care to be introduced gradually to complement disease modifying treatment and provide supportive care for bereaved family members (Fig 3 overleaf).

**Figure 3:** *Old and Trajectory Approaches to Palliative Care.* Source: Lynn (2003)



*Trajectory Approach to Palliative Care*



Despite the relative ‘malignant’ nature of heart failure (Stewart et al., 2001), access to palliative care is challenging. In a review of guidelines for the integration of palliative care for patients with non-malignant diseases in Europe, Siouta et al. (2016) note variations in deciding when to refer patients for palliative care. For example, the Gold Standard Framework prognostic indicator guidance in England (Thomas.K et al, 2011) uses NYHA staging (NYHA III/IV) to determine when to initiate palliative care. In Scotland, good communication is advised at diagnosis while management of physical,

spiritual and psychological issues is introduced according to patients' needs (The Scottish Government, 2008). The unpredictable nature of heart failure makes it difficult for health professionals to determine when a patient is approaching the end of life and if they would benefit from palliative care (Jaarsma et al., 2009). Health professionals may avoid initiating conversations about end of life care, preferring to maintain hope in the face of deteriorating health. (Low et al., 2011b ; Cheang et al., 2015).

Although patients with heart failure will ultimately die, palliative care should be triggered in the early stages and continue as the illness progresses. A complementary approach which combines disease modifying therapy with palliative care, and aims to gradually introduce palliative care according to patients' needs, provides optimum care for people living and dying with heart failure (Jaarsma et al., 2009).

## 1.5 Research setting

Participants for this study were recruited from Kiambu County (formerly district) Hospital. The hospital is located in Kiambu County which is one of Kenya's 47 devolved government units. The county is located in rural central Kenya and has a population of 1.6 million people over 2,543.5 square kilometres. Like most rural communities in Kenya, farming is the primary source of income (Kiambu County, 2016).

Kiambu County hospital (Figure 4) has 383 beds and it sits at the centre of the country's national health care referral system. It offers in and outpatient care to walk-in patients and those referred from lower level health facilities in the health system hierarchy. The hospital also refers patients to the national referral hospital for specialist care. The structure of Kenya's health system is discussed further in section 1.6.

**Figure 4:** Kiambu County Hospital. Source: Author's own

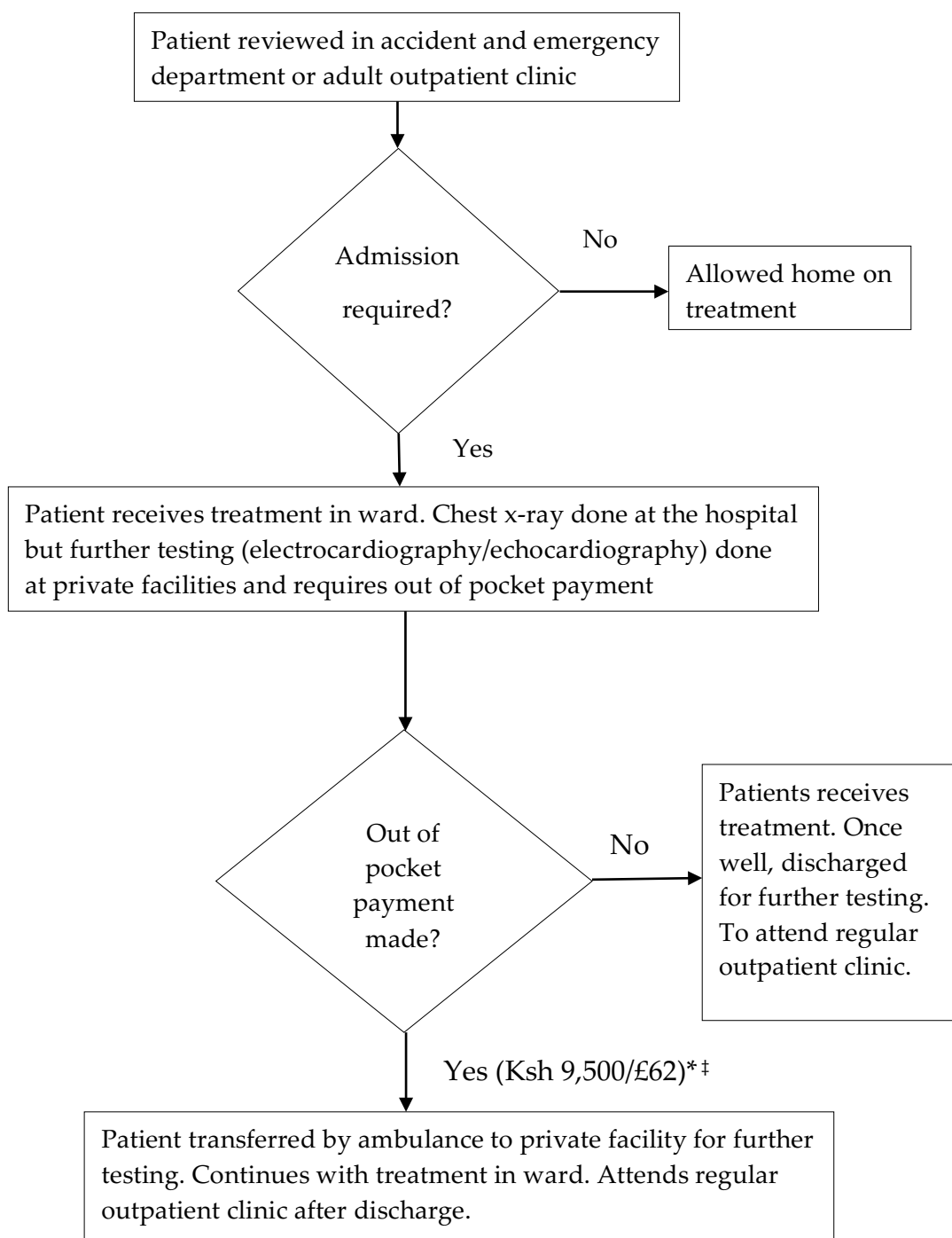




## Admissions process at the hospital

Figure 5 below represents the flow of admission for patients with heart failure at Kiambu County Hospital.

**Figure 5:** Admission procedure for patients with heart failure at Kiambu County Hospital



*\*Based on cost /exchange rate during fieldwork (2014/2015)*

*‡82% of Kenyans are informally employed (not on a payroll).*

*75% earn Ksh 1,000-9,000 (£7-70) per month.*

*Source: World Bank (2013) ; World Bank (2016)*

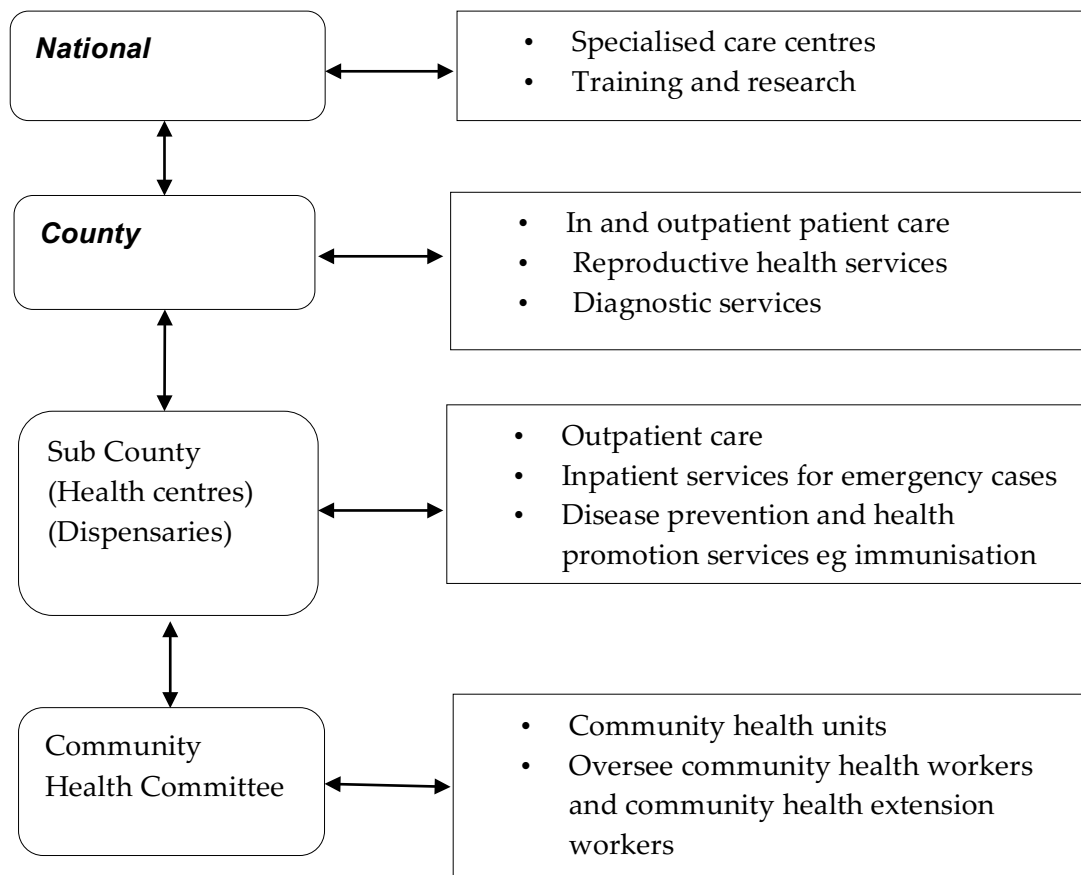
## **1.6 Kenya's health care system**

There are more than 8,000 health facilities in Kenya: 52% are government run, 31% are privately owned, and 14% are run by faith-based organizations (KNBS, 2010). The Kenyan public health care system functions at two levels: (i) national level and (ii) county level. At the national level, the ministry of health and auxiliary government agencies such as national hospitals, research institutions, the national insurance fund, and medical supplies bodies work together to support national health programmes (GOK, 2012 ; Muga et al., 2005). Two national referral hospitals provide advanced care: Kenyatta National Hospital and Moi Teaching and Referral Hospital (GOK, 2012).

In 2010, 47 devolved county government units were created. They are mandated to provide public services including health care (KLR, 2012). In each county, health care services are provided by community health committees, sub-county health facilities (health centres and dispensaries), and county hospitals. Figure 6 overleaf is a representation of Kenya's public health care system.

**Figure 6: Level and Function of Public Health Facilities in Kenya**

Source: Adapted from Kenya Health Policy (2012-2013)



## 1.7 Heart Failure in Kenya

NCDs are an emerging major public health concern for the country. They are the second major leading cause of death (28% of all deaths) after both communicable diseases and maternal, perinatal, and nutritional conditions (WHO, 2011).

Like other countries in SSA, population-based data on heart failure in Kenya remains scarce. A few hospital-based studies, reported in published papers and masters' dissertations, have identified hypertension, cardiomyopathy,

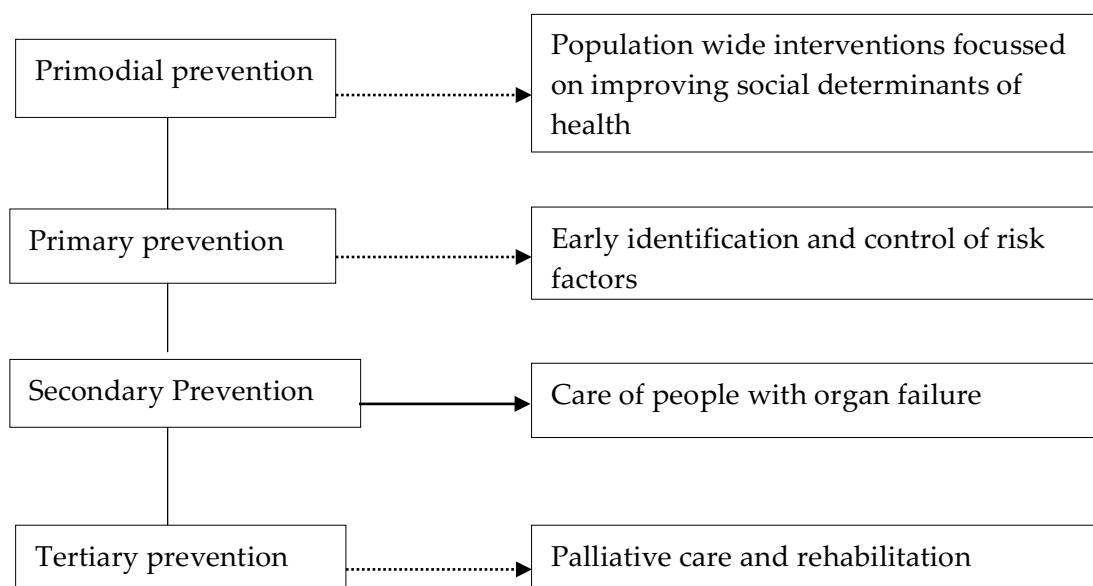
rheumatic heart disease and pericardial diseases as common causes of heart failure. Heart failure accounts for 5-6% of hospital admissions with most patients admitted in advanced stages of illness (Oyoo and Ogola, 1999 ; Mburu, 2012 ; Kamau, 2009 ; Barasa, 2009). In 2013, Kiambu County reported the highest proportion (11%) of the total number patients (452,940) treated for hypertension in the country (KNBS, 2016).

Kenyan ministry of health officials and cardiologists do express concern over the limited evidence base on heart failure in the country. They advise that research is urgently needed to guide patient care. However, a predominant focus on communicable diseases and maternal and child health programmes means heart failure research may not be viewed as an urgent priority. This is despite emerging evidence suggesting that heart failure is a leading form of cardiovascular morbidity and mortality in SSA (Ntusi and Mayosi, 2009) (ministry of health official, personal communication, April 2015).

Despite these challenges, the Kenyan government has made some progress in providing guidance for the care of people with heart failure. For instance, a heart failure treatment protocol was published in 2002 as part of a manual on the treatment of common conditions in Kenya. This treatment protocol covers the diagnosis of heart failure and the management of physical symptoms (WHO, 2002). Additionally, in 2015, a national policy for prevalent NCDs (cancer, diabetes, cardiovascular diseases, chronic obstructive pulmonary disease (COPD) and mental disorders) was published. This policy recommends a multisectoral approach to raise awareness on NCDs. Specifically, it supports holistic interventions aimed at supporting disease prevention and control, reducing risk factors, improving data surveillance, strengthening health systems, and promoting research to guide evidence-based practice. This policy also recommends primary,

secondary, and tertiary interventions (including palliative care) for chronic disease care (GOK, 2015) (Figure 7). A national strategy to guide the care of patients with heart failure is yet to be developed.

**Figure 7:** Framework for the prevention and control of non-communicable diseases in Kenya. Source: GOK (2015)



## 1.8 Palliative care in Kenya

Kenya's first palliative care unit was established in 1990. Ruth Woodridge, a British nurse, initiated the Nairobi Hospice as the first standalone unit to offer outpatient palliative care services in Kenya and the greater East Africa region. Since then more hospices have been set up to meet the growing need for palliative care, especially for patients diagnosed with terminal cancer. In 2005 the Kenya Hospice and Palliative Care Association (KEPHCA) was registered as the national organization responsible for coordinating hospice and palliative care services in the country (KEHPCA, 2016).

In 2014, The global atlas of palliative care at the end of life (WPCA, 2014) categorized Kenya as a group 4a country in the development of palliative services. Categorisation ranges from group 1 which means a country has no known hospice-palliative care activity to group 4b where integration of palliative care services into national health systems is at an advanced stage. Kenya's 4a status means that the country has achieved critical mass in palliative care advocacy, enhanced access to essential drugs (morphine), strengthened palliative care training and education, and supported a palliative care national policy and the formation of national palliative care association.

To guide palliative care practice, several guidelines are currently available in Kenya. These include (i) a guideline supporting holistic care for life-threatening conditions (ii) a national palliative care training curricula (iii) a national guideline for cancer management (KEHPCA, 2016). Additional resources have been published by the African Palliative Care Association (APCA) to guide advocacy, training, pain management, access to essential medicines, care for patients with HIV and cancer, and monitoring and evaluation of palliative care services (APCA, 2014).

Since 2007, KEHPCA and the ministry of health have received support from international partners to integrate palliative care services into the country's public health care system. For example, the multi-country THET (Tropical Health Education Trust) Integrate Palliative Care Project (2012-2015) led by partners at the University of Edinburgh, Makerere Palliative Care Unit in Uganda and the APCA, championed the integration of palliative care in four African countries (Kenya, Uganda, Rwanda, and Zambia). In Kenya, this project has aided community, hospital and national based palliative care advocacy; built capacity by training health professionals and community

volunteers; supported palliative care service delivery including improving access to morphine (DFID, 2015).

## **1.9 Chapter Summary**

This chapter reviewed the burden of heart failure in SSA and Kenya. It also examined international perspectives on the experiences of patients living and dying with heart failure. This chapter concluded with a description of the research setting. The next chapter presents an empirical and theoretical literature review identifying gaps in knowledge to support this study's research aim and questions.

## **Chapter 2 : Literature review**

A literature review seeks to identify, summarise, and critique existing literature to single out research gaps and establish a foundation for advancing knowledge. This chapter details empirical and theoretical literature informing this research. The first section outlines an updated scoping review of heart failure in SSA. This review is published in *BMJ Supportive and Palliative Care* (Kimani et al., 2016a). A copy of this paper is included in Appendix 1. The second section reviews sociological perspectives of living with chronic illness and outlines African perspectives on health and illness. This chapter concludes with this study's research aim and questions.

### **2.1 Scoping review: What is known about heart failure in Saharan Africa?**

Scoping reviews are gaining popularity as a method of identifying and critiquing research evidence. In a recent report of scoping reviews, Peterson et al. (2016) describe a significant increase in the publishing of scoping studies in multiple fields such as social work, public health, and nursing. The aim of scoping reviews is to explore the breadth and depth of published literature with the intention of mapping out what is already known about a particular topic so as to identify gaps and establish a foundation for advancing knowledge (Arksey and O'Malley, 2005). Given the anticipated paucity of literature on heart failure in SSA (as discussed in Chapter 1), a scoping review was deemed appropriate to consider evidence from an emerging field with the aim of identifying gaps in the knowledge base (Levac et al., 2010).



While there is no clear-cut methodology for carrying out a scoping review, Arksey and O'Malley (2005) suggest a multistage approach. This methodology includes (i) identifying the research question of interest (ii) identifying relevant studies (iii) selection of studies (iv) charting data (v) collating, summarising and reporting results.

### **2.1.1 Scoping review: Methodology**

This review was guided by Arksey and O'Malley's (2005) approach to scoping reviews.

#### **Stage 1: Identifying the research question of interest**

The research question to be addressed is: What is known about heart failure in Sub-Saharan Africa?

#### **Stage 2: Identifying relevant studies**

To identify pertinent literature, a search strategy combining key disease and study location terms was used (Table 2 overleaf). Study location terms were based on the World Bank's (2014) classification of countries in SSA.

Electronic databases searched included Web of Science, EMBASE, Ovid MEDLINE, PsychINFO, Global Health, CINAHL and African Journals Online. Search strategies were modified for each database and were supplemented by reviewing reference lists and websites of key organisations such as the World Health Organisation (WHO).

**Table 2:** Literature search strategy

	OR	OR
AND	<b>Disease terms</b>	<b>Study location terms</b>
	Heart failure Cardiac failure Congestive cardiac failure	Africa, sub Saharan Africa, Angola, Benin, Botswana, Burkina Faso, Burundi, Cabo Verde, Cameroon, Central African Republic, Chad, Comoros, Congo, Democratic Republic of Congo, Cote d'Ivoire, Eritrea, Ethiopia, Gabon, The Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, Sao Tome and Principe, Senegal, Seychelles, Sierra Leone, Somalia, South Africa, South Sudan, Sudan, Swaziland, Tanzania, Togo, Uganda, Zambia, Zimbabwe

### **Stage 3: selection of studies**

The following inclusion criteria guided selection:

- original research articles published in English
- studies with participants aged 18 and above.

Editorials, commentaries and case studies were excluded. Papers focused on physiological processes, pharmaceutical development, those without full-text versions and papers published prior to the year 2000 were also excluded.

#### Stage 4: charting data

Data from full text original articles were charted as follows: author(s), year of publication, country, aim(s) of the study, study methods, population and key findings.

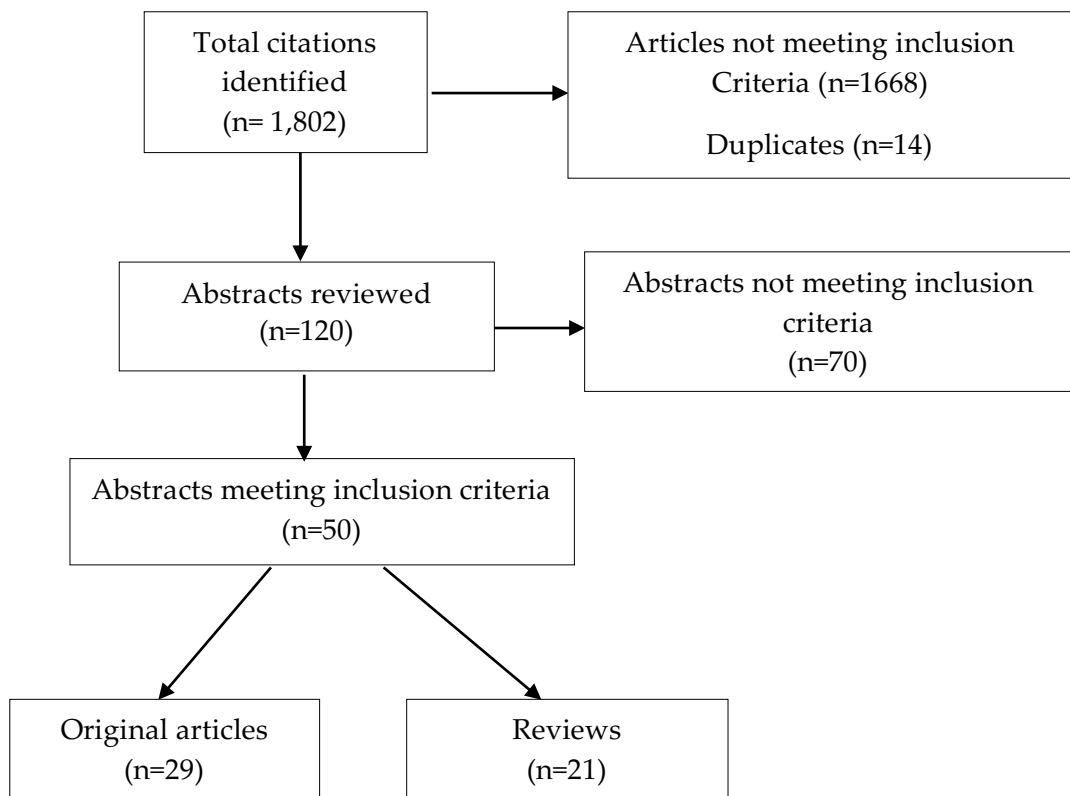
#### Stage 5: Collating, summarising and reporting results

Articles were then summarised and reported according to main themes identified. These are discussed in the next section.

### 2.1.2 Scoping review: Results

A total of 1802 citations were identified, and 120 abstracts were deemed relevant. Based on the inclusion criteria 50 articles were reviewed: 29 original full-text articles and 21 review articles (Fig 8). This review discusses the original articles identified.

**Figure 8: Literature identification and selection process**



Full-text articles reported the results of research conducted in the following African countries: Nigeria (n=16), South Africa (n=3), Cameroon (n=2), Tanzania (n=1), Ghana (n=1), Kenya (n=2), Zimbabwe (n=1) and Rwanda (n=1). Two additional papers described the results of a nine-country survey from the following African countries: Sudan, Ethiopia, Uganda, Kenya, Mozambique, South Africa, Cameroon, Nigeria, and Senegal.

All full-text articles analysed data from observational clinical studies or studies reviewing hospital medical records. In updating this review, one new article (Bloomfield et al., 2016) was identified. This article reported the results of a study conducted to determine the aetiology and clinical characteristics of patients with heart failure in western Kenya. Appendix 2 includes a table of full-text articles retrieved for this review.

In reviewing the 29 full-text articles, three themes were identified: (i) the epidemiology of heart failure (ii) patients' psychological burden and (ii) patients' level of knowledge and adherence to treatment. Table 3 below summarises these themes.

**Table 3:** Summary of themes identified from scoping review

Epidemiology of heart failure	Patients' psychological burden	Patients' level of knowledge
<ul style="list-style-type: none"> <li>• Heart failure occurs two decades earlier compared to western countries</li> <li>• Accounts for 9-15% hospital admissions</li> <li>• Leading causes of heart failure: hypertension, dilated cardiomyopathy, rheumatic heart disease</li> </ul>	<ul style="list-style-type: none"> <li>• Depression and anxiety is common</li> <li>• Younger patients experience more psychological distress</li> </ul>	<ul style="list-style-type: none"> <li>• Poor knowledge levels for medication</li> <li>• Poor adherence to treatment especially diuretics</li> <li>• Health education improves knowledge scores</li> </ul>

## **Epidemiology of heart failure**

Heart failure accounts for up to 15% of hospital admissions in SSA. The leading cause of heart failure is hypertension (8-78%). Other causes include cardiomyopathy (7.5-54%), rheumatic heart disease (2.4-25%), chronic obstructive pulmonary disease (4.4–27%), and congenital heart diseases (3%). In the past, ischemic heart disease (IHD) was not regarded as a leading cause of heart failure in SSA. However, a recent study conducted in western Kenya by Bloomfield et al. (2016) found that IHD caused 18% of 125 cases of heart failure.

From the full-text articles reviewed, the age range for heart failure patients in SSA is 29-73 years. (Makubi et al., 2014 ; Ogah et al., 2014 ; Ojji et al., 2013 ; Kwan et al., 2013 ; Damasceno et al., 2012 ; Tantchou Tchoumi et al., 2011 ; Onwuchekwa and Asekomeh, 2009 ; Stewart et al., 2008b ; Karaye and Sani, 2008 ; Amoah and Kallen, 2000 ; Bloomfield et al., 2016). Several risk factors for heart failure have also been identified. In Kenya, Lagat et al. (2014) found that exposure to occupational dust, a decrease in household kitchen ventilation and a decline in lung function increases the risk of right-sided heart failure. In Nigeria, Laabes et al. (2008) identified consumption of alcohol and obesity as risk factors. Viruses such as HIV and enteroviruses have been linked to heart failure in Kenya and West Africa (Okonko et al., 2013 ; Lagat et al., 2014). From studies in Cameroon, common comorbid conditions include chronic kidney disease and chronic lung disease (Dzudie et al., 2008). These conditions, in addition to cancer and HIV, are predictors of mortality (Sliwa et al., 2013).

## **Psychological burden**

Using the Hospital Anxiety and Depression Scale, Ansa et al. (2009) found that nearly 40 of 100 Nigerian patients with heart failure had depression and anxiety. In a similar Nigerian study, depression was found in almost 60% of 122 patients admitted with heart failure and in 30% of 82 outpatients (Mbakwem et al., 2012). Anxiety and depression were found to have a more adverse effect on quality of life in younger patients (Ola et al., 2006 ; Adewuya et al., 2006).

## **Patients' knowledge levels and adherence to treatment**

In evaluating 200 South Africans with heart failure, Ruf et al. (2010) found that patients knew little about their treatment. Most patients (56%) were unaware of the side effects of their prescribed medication and adherence to diuretics, mainly furosemide, was low as patients avoided its side effects. However, patients who received education on heart failure management had higher illness knowledge scores. Bhagat and Mazayi-Mupanemunda (2001) report similar results in their study of 22 heart failure patients in Zimbabwe. Thirty percent (30%) of patients reported poor treatment adherence and half were not able to recall their prescription correctly.

## **2.2 Critique of empirical literature**

Since 2000, research on heart failure in SSA has focused predominantly on quantitative studies to determine disease burden. Although these studies may be necessary for quantifying an emerging health issue, quantitative methods may not suffice for capturing personal experiences. Quantitative

methods rely on objective numerical data which may not allow in-depth exploration of patients' experiences. Instead, qualitative methods enable people to use their words to express their thoughts and feelings on how they make sense of life experiences (Braun and Clarke, 2013:24). Qualitative methods generate rich textual data which allows for further understanding of people's needs. (Thorne et al., 2002). In SSA, research on the experiences of patients with heart failure is required to identify what is important to patients and suggest how to develop and improve health services.

## **2.3 Sociological perspectives on living with chronic illness and heart failure**

This section aims to review literature on the sociological perspectives of chronic illness. Heart failure is regarded as an emerging chronic condition in SSA (Bloomfield et al., 2013) and conceptual theories around chronic illness may help to frame our understanding of this phenomenon. Although the context of chronic illness in SSA may differ with the western context where these conceptual theories were developed, we should be cautious of stereotyping the African context as different at the expense of the normative experience of living with chronic illness (de-Graft Aikins et al., 2010a)

To structure our understanding, this section begins by tracking earlier work developed by Parsons (1975), Bury (1982), Charmaz (1983) and Williams (1984) to explore how conceptual theories of how people make sense of chronic illness have evolved. It follows with a review of the progression of research exploring the experiences of patients with heart failure.

Sociological perspectives on living with chronic illness aim to explain how people with chronic illness conceptualise their experience. These

perspectives go beyond describing physical symptoms to explore how illness affects people's lives including their relationship with self and others. Two important sociological approaches have been essential in understanding the experience of living with chronic illness and have informed this study:

(i) Parsonian theory of sick role (Parsons, 1975) and (ii) empirical enquiry into chronic illness including the work of Michael Bury (1982), Kathy Charmaz (1983) and Williams (1984).

In his pioneering concept of the sick role Talcott Parsons (1975) underscores the fact that the association between disease and patient experience is not limited to biology but is influenced by socio-cultural context as sick people are assigned social roles (known as sick role) with rights and responsibilities. Illness is regarded as a legitimate state of deviance in which a person is exempted from certain social roles, such as days of work, with the expectation that they will seek help to maximize their chances of recovery (Parsons, 1975). Although Parson's theory has been helpful in our understanding of patients' experiences, it has received criticism for its usefulness in understanding chronic illness. Radley (1994) suggests that sick role theory may not adequately explain the unique experiences of people with chronic illness. In sick role, a person is motivated to get better, which may not be possible for people suffering with poor health over long periods (Crossley, 1998 ; Kassebaum and Baumann, 1965).

In response to the limitations of Parson's theory, Michael Bury's (1982) paper 'Chronic illness as a biographical disruption' is widely regarded as a significant text in understanding lay experiences of chronic illness. From interviews with patients with rheumatoid arthritis, Bury (1982) describes chronic illness as a 'biological disruption' (199:1982) occurring at three levels. First, is a 'disruption of taken for granted assumptions' (169:1982) in which



symptoms are explained using a common sense approach. For example, participants in Bury (1982) study assumed their symptoms were a consequence of daily work. Most participants were young and perceived arthritis as a disease for older people. However, as symptoms persisted a common sense approach could no longer hold. At the second level, further disruption of explanatory mechanisms leads to questions such as 'why me?' (174:1982). Disruption of these mechanisms involves a re-thinking of self as patients looked into past events to make sense of their experience. The final stage involves mobilising personal relationships and other physical resources (such as finances) to respond to disruption (175-77: 1982). Failure to mobilise adequate resources leads to a new crisis and deepens disruption.

In her approach to chronic illness, Kathy Charmaz (1983) criticises a narrow medicalised viewpoint which limits suffering to physical discomfort. Drawing upon interviews with patients diagnosed with chronic illness, Charmaz (1983) identified 'loss of self' as part of the broader suffering experienced by patients. Sources of 'loss of self' include social isolation, feeling discredited by self and others, becoming a burden and living a restricted life. These sources are interdependent with loss of self in one area amplifying another. For example, a reduction in physical functioning may limit participation in previously enjoyed activities, which may lead to social withdrawal and isolation (172-190:1982).

Williams (1984) moves past Micheal Bury's (1982) biographical disruption and Kathy Charmaz's (Charmaz, 1983) loss of self to explain the experience of chronic illness as a narrative reconstruction in which people employ strategies to repair a disrupted self by finding purpose in their illness and placing it in the context of their daily lives. Narrative reconstruction aims to 'repair and reconstitute ruptures between body, self, and world by linking

up and and interpreting different aspects of biography in order to realign present and past and self with society' (Williams, 1984:197). In an interview study with patients with rheumatoid arthritis, Williams (1984) found that people's accounts of disease causation went beyond the biomedical model to incorporate their past experiences and aspects of their social context. In an overview of research exploring lay experiences of health and illness, Lawton (2003) notes the value of acknowledging how macro and micro-context, such as sociodemographics and interpersonal relationships impacts peoples experiences and our understanding of chronic illness. Although Bury (1982) points to this important role in his description of the third level of disruption in which physical resources and social relationships are mobilised to respond to disruption, Lawton (2003) suggests that more work needs to be done to account for the ever changing contexts in which chronic illness occurs.

Like chronic illness our understanding of the experiences of living with heart failure has evolved over time, from initial cross sectional qualitative studies aimed at identifying themes that characterise patients' experiences, to longitudinal studies exploring how patients' experiences change with time. Several qualitative systematic reviews aimed at collating and analysing research in this area, show that until recently, most studies exploring patients' experiences have employed a crosssectional design to identify unifying themes (Low et al., 2011a ; Jeon et al., 2010 ; Olano-Lizarraga et al., 2016). More recent work has taken a longitudinal approach and built upon the illness trajectory work as suggested by Lunney Jr (2003) and Lynn J (2003). For example, Gott et al. (2007) conducted a quantitative longitudinal study to identify dying trajectories in heart failure. In their findings, the authors did not identify a typical heart failure trajectory and suggested that

more research is needed to develop services that are underpinned by our understanding of patients' illness trajectory.

Qualitative longitudinal research by Boyd et al. (2004), Murray et al. (2007), Willems et al. (2004), Willems et al. (2006) and Klindtworth et al. (2015) provided a more nuanced understanding of how patients' experiences and needs change with time. Willems et al. (2004) tracked patients thoughts about death and dying as well as how they coped and adjusted to their illness (Willems et al., 2006). Similarly, Klindtworth et al. (2015) identified how patients adjusted to their illness, coped with end of life and how illness impacted personal relationships. Boyd et al. (2004) and Murray et al. (2007) identified patients' physical, social, spiritual and psychological needs and illustrated how these change with time. This longitudinal approach supports Lawton (2003) call for research that takes into consideration of the dynamic context in which chronic illness occurs. Research on the experiences of people with heart failure has so far been conducted in mainly high-income countries. Further research is needed to extend this work to other geographical and ethnic contexts (Hopp et al., 2010).

## **2.4 Concepts of health and illness in Africa**

For many communities in Africa, health and illness beliefs are embedded in the African worldview. This worldview is religious and emphasises a kinship among people, their environment, and the spiritual world. (Omonzejele, 2008).

In African communities, health is all-encompassing and not limited to physical functioning. Social, spiritual, emotional wellbeing along with maintaining good relations with the community are perceived as

contributors to good health. Disease is viewed as a two-fold concept: (i) as physical dysfunction of bodily organs and (ii) as a consequence of discord with the community or spiritual world (Omonzejele, 2008 ; White, 2015). For example members of the Abagusii community of southwest Kenya, associate tuberculosis with biological and spiritual factors such as witchcraft and sorcery (Mochache and Nyamongo, 2009). This dual understanding of illness may lead patients to seek modern and traditional medicine simultaneously. Other communities in Kenya express similar dual understanding. For instance, in traditional Kikuyu culture, illnesses were treated first using medical knowledge, and if this was not successful, a diviner was sought to communicate with ancestors to determine if an offence had occurred. If this also failed to provide a cure, the community would appeal to God for a cure (Kenyatta, 1937).

With the advent of Christianity in Kenya, traditional beliefs infused with Christian beliefs and practices. Although more than 80% of Kenyans currently ascribe a Christian faith (KNBS, 2010), it is not uncommon for Christian beliefs to co-exist with traditional religion. For example, in a study examining discontinuation of anti-retroviral therapy for HIV in an urban slum in Kenya, patients reported combining traditional approaches such as traditional herbs and prayers with conventional antiretroviral treatment. Many believed that traditional approaches and prayers would cure their illness (Unge et al., 2011). African and indeed Kenyan concepts of health and illness may differ from a modern biomedical model of medicine which explains disease in biological terms (Nettleton, 2006: 2). This may in turn influence the way people experience and make meaning of illness.

## **2.5 Justification for this study**

Findings from the above scoping review show that the experiences of patients with heart failure in SSA are yet to be described. So far, most studies exploring the experiences of patients with heart failure have been conducted in high-income countries. In an international review of palliative care in advanced heart failure, Low et al. (2011b) found that majority of qualitative studies (16 out of 28) exploring patients' experiences at the end of life were carried out in the United Kingdom with the other studies conducted in the United States, Netherlands, New Zealand, Sweden, Ireland and Canada. A similar review of the end of life experiences of patients with heart failure (Hopp et al., 2010) found that 11 out of 15 studies were conducted in Europe and four in the United States.

It is likely that differences may exist between the experiences of patients living and dying with heart failure in high-income countries and SSA. Already, differences have been identified in patients dying of cancer in an economically developed country (Scotland) and developing country (Kenya). In Kenya, cancer patients experience a significant pain burden while patients in Scotland are most concerned about dying (Murray et al., 2003). Furthermore, differences in sociodemographic characteristics may influence patients' experience. For instance, in SSA the age of patients with heart failure ranges from 29-73 years with the mean age being the fifth decade which differs with high-income countries where heart failure occurs in the seventh decade. For example, in the United Kingdom, a study of general practice database found the average age of heart failure patients was 77 years (de Giuli et al., 2005). Similarly, in the United States, a review of heart failure admissions found most patients averaged 72 years (Adams Jr et al., 2005). Although age differences may be indicative of variations in life expectancy

younger patients have been shown to report greater psychological distress as they struggle to cope with illness (Moser et al., 2013). This finding is reflected in the Nigerian studies (Ansa et al., 2009 ; Mbakwem and Aina, 2008 ; Ola et al., 2006) identified in the scoping review, which report poorer quality of life for younger patients with depression and anxiety. Additional differences from variations in social, cultural and health system contexts may also influence how people experience and interpret illness (Singer and Bowman, 2002).

In response to the rising burden of NCDs, the World Health Assembly adopted a resolution in the year 2014 to strengthen palliative care across the continuum of care. This resolution encourages research aimed at informing models of care particularly for resource poor-countries (WHA, 2014). Given the gap in knowledge in understanding the experiences of patients with heart failure in SSA, this research intended to generate evidence to inform practice and policy for the care of people living and dying with heart failure in SSA.

## **2.6 Research Aim and Questions**

Based on the research gap identified, this research aims to explore the experiences of patients living and dying with advanced heart failure in Kenya.

The research questions are:

1. How do patients describe their illness experience?
2. How do patients describe their experience with care?
3. What are patients' views on how their care can be improved?

## **2.7 Chapter Summary**

This chapter presented a review of empirical and theoretical literature that has informed this research. It identified a gap in knowledge in the understanding of the experiences of patients living and dying with heart failure in SSA. The next chapter outlines the methodological approach and methods used to conduct this research.

## **Chapter 3 : Conducting the research**

This chapter describes how this research was carried out. The first section begins with an overview of the philosophical assumptions guiding this research. This section is followed by an outline of methods, participant recruitment and data management. The chapter concludes with a section on reflexivity.

### **3.1 Philosophical assumptions guiding qualitative research**

Whether aware of it or not, personal beliefs and ideas may influence the way in which we conduct research. In qualitative research, it is commonly accepted that the researcher's worldview directs the research process. This worldview, also referred to as a philosophical assumption (Creswell, 2007:16-17), guides how the researcher formulates research questions, selects appropriate methods to generate data and interprets research findings. A researcher appraises their personal philosophical assumptions by considering how their views on ontology, epistemology and methodology may influence the research process (Crotty, 1998).

#### **3.1.1 Ontological position**

Ontology addresses the nature of reality and what can be known about it (Guba and Lincoln, 1994:108). It sets out to determine if reality exists externally from the human mind and if it is independent of one's consciousness, or if it is socially constructed. Views on ontology occur along a continuum. On one end 'realism' acknowledges that there is a single and independent reality yet to be discovered while on the other 'relativism'



suggests that there is no single external reality but rather multiple realities which can only be known through socially constructed meanings (Guba and Lincoln, 1994:105-117 ; Braun and Clarke, 2013:27).

This research is based on a critical realist ontology – a middle ground between a realist and relativist ontology. Critical realism recognises an external reality existing separately from our social constructions. Although the existence of an independent reality is assumed, knowledge regarding this reality is a construction shaped by our individual perspectives (Bhaskar, 2010:2). While a critical realist position might seem similar to a positivist realism which suggests a discernible objective reality, it acknowledges that it is impossible to have a single accurate view point regarding the nature of reality and that our understanding of reality will be imperfect (Guba and Lincoln, 1994:110 ; Maxwell, 2012).

### **3.1.2 Epistemological position**

Epistemology is a branch of philosophy that deals with the theory of knowledge and how knowledge is known. While various epistemological stances exist, Crotty (1998:8-9) mentions three positions: objectivity, constructivism, and subjectivism.

In an objectivist epistemology, reality exists independently from the subject and may be discovered using appropriate scientific methods. In contrast, a subjectivist epistemology rejects an objective reality and suggests that a subject imposes meaning on an object. A constructivist epistemology suggests that meaning is constructed by our minds engaging with an independent external world and that people may make different meanings when experiencing the same phenomena (Creswell, 2007:24-25 ; Crotty, 1998:8-9).

This research hinges on a constructivist epistemological position. It acknowledges that meaning is constructed by interacting with an external world. It also appreciates that we each have our unique way of making sense of the world. A constructivist epistemology acknowledges that divergent perspectives will result in different meanings (Crotty, 1998:57-58).

### **3.1.3 Choice of Methodology**

Methodology is the overarching framework guiding the research process (Creswell, 2007:21-22). It includes practices and procedures on how to conduct research (Braun and Clarke, 2013:31). According to Creswell (2007:22), qualitative research is a predominantly inductive approach which aims to build theory. Qualitative research begins with the identification of patterns in observable data and concludes with developing themes and broader generalisations. This inductive approach is different from a purely deductive approach that aims to test theory and determine whether pre-existing theory applies in a given circumstance.

This research relied on an inductive-deductive approach. This means that on the one hand, an inductive approach worked from the 'bottom up' by building themes from the data. On the contrary, a 'top-bottom' inductive method tested the themes emerging from the inductive process against the data and pre-existing theories. This cyclic activity between inductive and deductive approaches occurred throughout the research process (Creswell, 2007:45).

### **3.1.4 Personal stance**

To ensure rigour, a researcher should be reflexive about their personal stance and how this might influence their research project. A personal stance refers to the researcher's standpoint which is often shaped by multiple identities

such as age, social class or gender. These identities may influence how relationships with participants develop and in turn how the study is conducted (Bourke, 2014).

For this research, shared traits such as nationality, language, ethnicity, and gender may have helped in bridging connections with research participants (Sultana, 2007). However, these traits also created dynamics that influenced how this study was conducted. (Swift and Tischler, 2010). Chapter 9 provides an account of how my personal stance and multiple identities may have had an effect on the research process.

## **3.2 Methods**

### **3.2.1 Selecting a data generation method**

The main aim of this research was to explore patients' subjective experience of living with chronic illness. This aim guided the generation of data that intended to fill the research gap identified in Chapter 2. Qualitative methods were deemed most appropriate as they offer insight into people's life experiences. Unlike quantitative methods that collect numerical data to perform statistical analyses, qualitative approaches, at their core, aim to generate data in the form of text to explore, describe and develop our understanding of how people make meaning of social phenomenon (Braun and Clarke, 2013:20-23).

In conducting a qualitative study, a range of methods are available to facilitate data generation. These include interviews, focus groups, observations (such as ethnography), visual and other forms of electronic data. A study's research question should guide the selection of a suitable method.

For this study, interviews were selected as the most appropriate method to support data generation. Interviews allow for in-depth exploration of individual accounts, which is less likely to occur in focus groups that use group discussions to explore a subject of interest. Additionally, interviews allow discussion of sensitive issues, which may be difficult to speak about in group discussions. Although focus groups may enable participants to reflect on and respond to what they hear from others, group dynamics may interfere with how participants respond during discussions. Focus groups are more appropriate for participants who are comfortable with each other, have a shared background and can travel to attend a group discussion. While participants in this study shared a diagnosis, they were likely to have unique needs. Also, the nature of their illness may have limited their ability to travel to attend a focus group discussion. After considering the appropriateness of each method, individual serial face-to-face interviews were selected as best suited to facilitate data generation for this study. Observation methods were not deemed appropriate, as participants were not taking part in a public action that could be observed. Electronic methods such as email interviewing were not feasible or accessible for the local context in which this study was conducted (Ritchie et al., 2014:52-59 ; Braun and Clarke, 2013:113).

### **3.2.2 Qualitative interviewing**

Conversation is fundamental to human interaction. It is through speaking to one another that we learn about people's experiences, beliefs, values, fears and hopes for the future (Brinkmann and Kvale, 2015:1-3). In qualitative research, interviewing is the most common approach to generating data on personal and social experiences (Holstein and Gubrium, 1997:99). Unlike day to day conversation, qualitative research interviews aim to seek a deeper

understanding of how people view their world and how they make meaning of their experiences (Brinkmann and Kvale, 2015:2-3).

Face to face interviewing is considered the 'gold-standard' for generating data for qualitative research. In this type of interview, a researcher and participant engage in a spoken conversation to explore a phenomenon of interest. The researcher asks a series of questions which the participant responds to using their words. The advantage of face-to-face interviews is that social cues such as body language, intonation, and facial expression can be observed. These may add vital information to the spoken conversation by pointing to new issues to be explored or by identifying sensitive topics causing unwanted distress to participants. Given the sensitive nature of this research and the vulnerability of the participants taking part in this study, face to face interviewing was deemed most suitable for generating data. Other forms of interviewing such as telephone email and virtual methods were unfeasible for this type of research and the local context in which it was conducted (Opdenakker, 2006 ; Braun and Clarke, 2013:79-80).

### **3.2.3 Longitudinal qualitative methods**

Longitudinal qualitative methods aim to incorporate time into the research process by making change a principal focus of analysis (Saldana, 2003). These methods have considerable use in anthropology (Clark et al., 1995), psychology (Hughes and Dunn, 2002), education and childhood studies (Saldana, 2003:1-3). Longitudinal qualitative methods mainly use interviews and/or observation techniques to generate data although other techniques may be applied. Irrespective of the technique, a study's design should focus on the length of time engaged in data generation (Saldana, 2003:16).

This study used serial qualitative interviews to generate data. These methods incorporate time and change into a study's design and are useful for understanding patients' dynamic needs and experiences. Unlike single interviews, serial interviews allow for trusting relationships to develop between a researcher and a participant. Trusting relationships help participants feel more comfortable to discuss sensitive issues which may be difficult to talk about during a single interview (Murray et al., 2009). Serial qualitative interviews have been used to explore the experience of living with chronic illness in other settings (Pinnock et al., 2011 ; Cavers et al., 2012 ; Morris et al., 2011).

For this study, up to three semi-structured face-to-face interviews with each patient over a 6-month period were undertaken. Interviews were conducted at month 0, month 3, and month 6 after recruitment. However, interview timings were flexible and dependent on a patient's health status or the occurrence of an event, such as a hospital admission, which might have triggered an earlier or later interview.

Selection of interview timings was based on existing knowledge on the trajectory of heart failure. Heart failure is an unpredictable illness in which patients alternate between stable periods and episodes of acute crisis. Sudden death is also a possibility and may occur at any point along the course of illness (Jaarsma et al., 2009). Cohort studies conducted in the United Kingdom (Cowie et al., 2000) and the United States (Goldberg et al., 2007) indicate that after diagnosis, 25% and nearly 40% of heart failure patients die within 3 and 12 months, respectively. Due to differences in health system and socio-economic contexts, a higher rate of readmission and mortality in the Kenyan population was expected (Yusuf et al., 2014). A

flexible approach to interviewing and short intervals between interviews was helpful in capturing the needs of patients at critical points of their illness.

### **3.2.4 Topic guides**

A topic guide was used to steer the interview and outline key themes to be explored. Although the topic guide was structured into themes to safeguard data uniformity, it gave room to explore issues unique to individual participants (Ritchie et al., 2014:149). The topic guide for this study examined patients' subjective experience of living and dying with heart failure with special focus on aspects relevant to palliative care. Specifically, it explored (i) patients' physical, social, psychological and spiritual experiences (ii) their experiences with care and (iii) how their care could be improved. Similar topics were explored with carers. Appendix 3 and 4 shows interview topic guides for patients and carers, respectively.

## **3.3 Participation**

### **3.3.1 Sampling**

Sampling is the process of selecting a smaller group of individuals to represent a larger group (or population) to be studied (Braun and Clarke, 2013:55). Qualitative and quantitative research methods differ in their approach to sampling. Quantitative research methods rely on probability sampling to select large, random and statistically representative samples so that results can be applied to a larger group (Ritchie et al., 2014:112).

Conversely, in qualitative inquiry, sample sizes are smaller. Unlike quantitative methods which aim at selecting statistically representative samples, qualitative methods aim to select samples with attributes of interest from a larger population (Braun and Clarke, 2013:56 ; Ritchie et al., 2014:112).

The question of sample size in qualitative research has evoked divergent views. Charmaz (2012) advises that sample size should be guided by the need for rigour. Adler and Adler (2012) suggest that sample size should be directed by a researcher's need to gain experience in conducting qualitative research and should range between 12-60 interviews. Becker (2012) proposes that sample size should be sufficient to meet the study's objectives and justify conclusions made.

This study recruited 20 patients admitted with a diagnosis of advanced heart failure at a district hospital in Kenya. This study's sample size was based on previous longitudinal qualitative research on advanced illness suggesting sample sizes of 20-25 people are sufficient to approach data saturation (Worth et al., 2009 ; Boyd et al., 2004), and the need to hone my skills in longitudinal qualitative methods as part of my PhD training (Adler and Adler, 2012).

### **3.3.2 Purposive sampling**

Purposive sampling involves the deliberate selection of diverse sampling units to offer an in-depth understanding of a phenomenon of interest. Participants are selected based on the characteristics they possess such as their age, gender or socioeconomic status. Purposive sampling aims to include all key characteristics which may be relevant to the topic being studied (Ritchie et al., 2014:113 ; Braun and Clarke, 2013:56).

To ensure a diverse sample, a sampling frame was used to select patients to represent various causes of heart failure, and the age, sex and level of education of the population under study. In this sampling frame, level of education acted as a proxy for socio-economic status (Appendix 5).



### **3.3.3 Study participants**

Study participants (patients and carers) were recruited based on the following inclusion and exclusion criteria.

#### **Patient's inclusion criteria**

- Patients admitted and diagnosed with advanced heart failure as confirmed by clinical signs and symptoms based on NYHA classification (World Health Organisation, 2009 ; Davies et al., 2000)
- Objective signs of heart failure on chest x-ray, echocardiography or electrocardiography
- Patients who could communicate in English or Kiswahili
- Patients who lived within 35 Km from the recruiting hospital.

#### **Patient's exclusion criteria**

Patients who at recruitment were diagnosed with another life limiting illness (such as cancer or advanced HIV) requiring most care, those cognitively impaired, unable to communicate in Kiswahili or English, below 18 years or living 35km beyond the recruiting hospital.

#### **Carer inclusion criteria**

- Chosen by a patient
- Lived within 35 Km from the recruiting hospital
- 18 years and older

#### **Carer exclusion criteria**

Carers who were not able to communicate in English or Kiswahili or living 35km beyond the recruiting hospital.

### **3.3.4 Recruitment procedures**

Prior to recruitment, the physician in-charge of the adult medical wards was introduced to the study. Ward staff (doctors/nurses) were invited to a seminar to familiarize them with the study and its recruitment procedures. Ward staff willing to take part and recruit participants were identified and each provided with a study information pack. Each pack contained participant information sheets and consent forms for the participating patients (Appendix 6-9). Figure 9 on page 47 outlines participant recruitment.

Once a doctor or nurse had identified a patient fitting the inclusion criteria, they approached and informed the patient about the research. The patient was offered an information pack (patient information sheet and consent form; Appendix 6-9) and asked for permission to pass on their name to the researcher. If a patient was willing to take part, their basic patient information (sociodemographic data and clinical details) was recorded in the patient recruitment form (Appendix 10) and handed over to the researcher to confirm eligibility. If a patient was not willing to participate, no further action was taken, and anonymised details of their diagnosis, age, sex, level of education, and the reason(s) for declining to take part were recorded to compare with those who chose to participate (Appendix 11).

If a patient was found eligible and well enough to take part, they were approached to discuss the research and answer any questions they had. After 24-48 hours, the patient was contacted again to confirm participation. If a patient was not willing to take part, they were thanked and no further action taken.

For patients willing to take part, they were informed that they had the choice of inviting their carer (or the person who best fits the description –‘the

person who takes care of them') to be interviewed in their place if or when their condition deteriorated and they were not able to take part in an interview. If willing to invite their carer, a patient was offered: (i) a letter inviting the carer to participate in the study (ii) carer information sheet and (iii) carer consent form (Appendix 12-17) to pass on to their choice of carer. If a patient was not willing to choose a carer, their decision was respected, and a convenient date, time and place was set for the first interview.

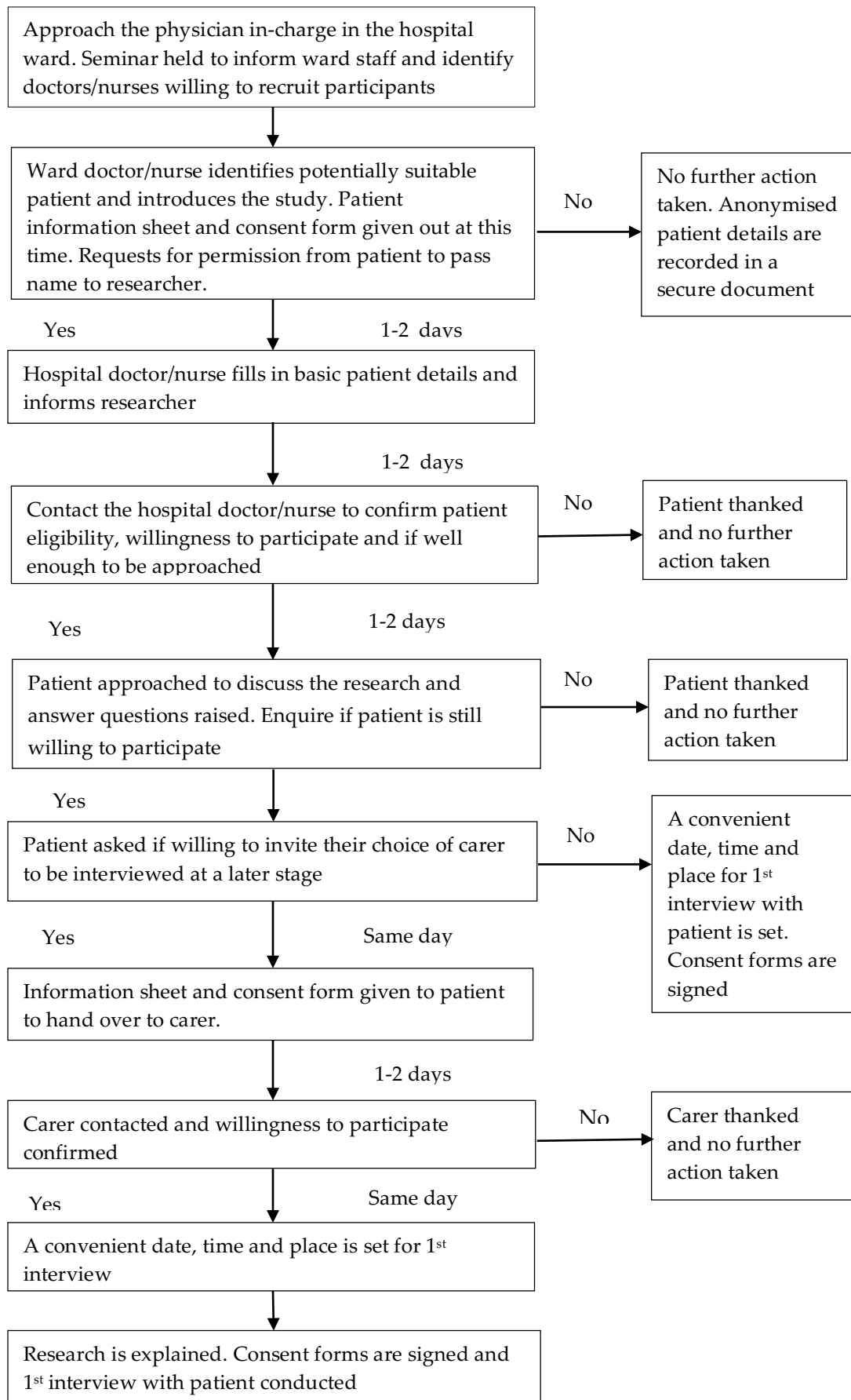
Nominated carers were contacted after 24-28 hours to discuss the research and answer any questions they had and confirm eligibility. If they were willing to participate, the first interview was scheduled at a convenient time. Consent forms were signed before commencing the interview.

The rationale for recruiting carers was two fold. First, an after death interview with a carer is a source of valuable information for understanding dying experiences when a patient's well-being is declining (Addington-Hall and McPherson, 2001). Second, recruiting carers provided an opportunity to observe who patients regarded as the 'person who takes care of them'.

Historically in most African countries the nuclear and extended family is regarded as a source of physical, social and economic support and family members may find themselves providing informal care to those who are chronically ill. In Kenya where palliative care services are limited and the cost of medical care is prohibitive, home based family caregiving is a necessity. However, the financial burden from health care costs and basic needs as well as work commitments, may limit the capacity and the will for family members to provide long term informal care (Githaiga, 2015) .

Observing who was chosen as a carer provided an opportunity for nuanced understanding of support systems available to patients.

**Figure 9: Participant (patient and carer) recruitment flow chart**



## **3.4 Data generation**

### **3.4.1 Interviews**

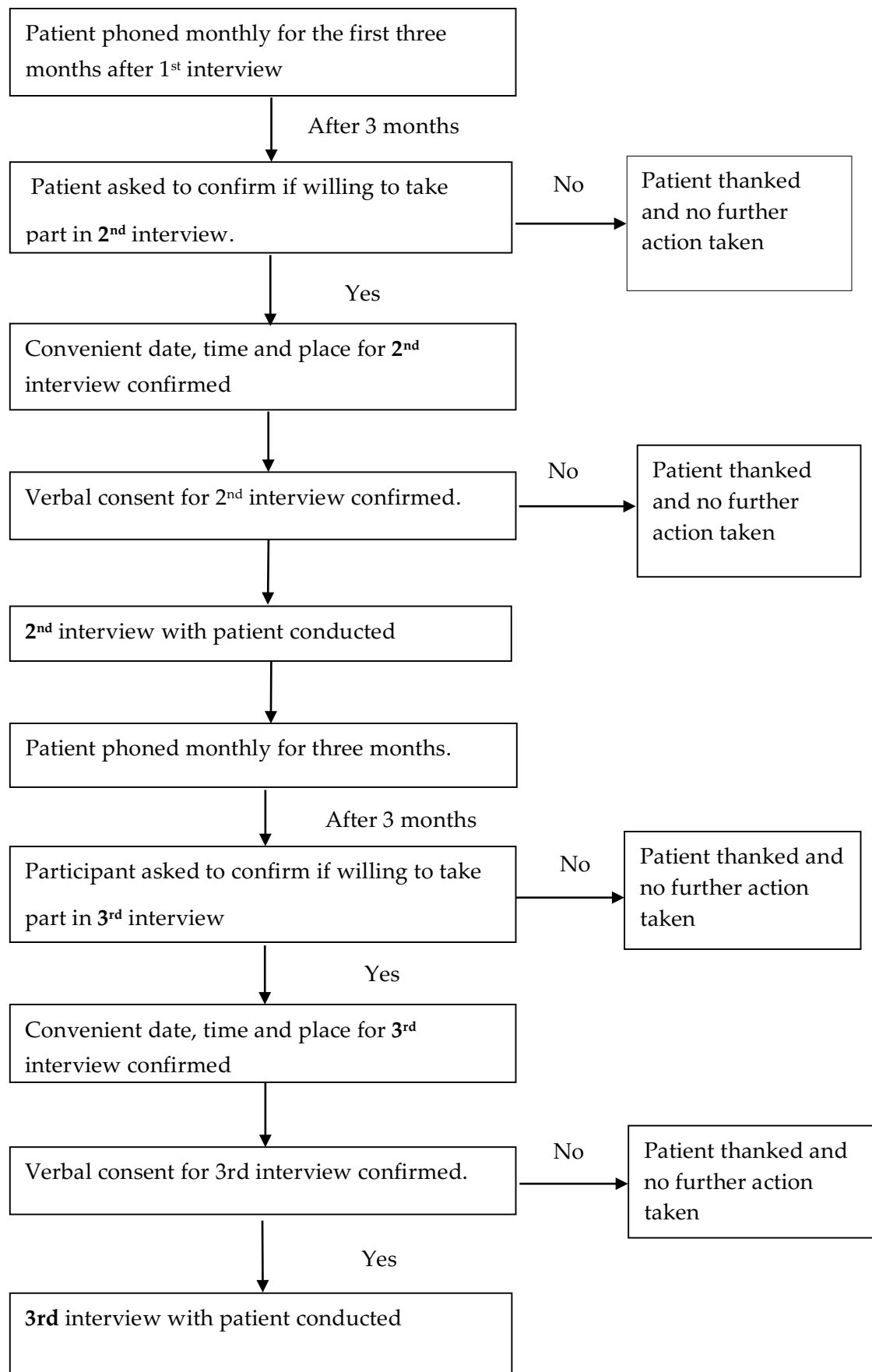
#### **First interviews**

These interviews took place in the hospital ward or at a patient's home. Before the interview, the purpose of the research was explained, and patients were reminded their participation was voluntary and that they could withdraw at any point during the study period. If still willing to participate, the consent form was signed, or an inked thumbprint was used if they were unable to write.

#### **Subsequent interviews (second and third interviews)**

Second and third interviews were conducted three and six months after the first interview. However, this was flexible to capture significant events, such as an admission that might have impacted a patient's experience and triggered an earlier interview. In between interviews, patients were phoned monthly to record any changes in their condition, maintain contact and schedule follow-up interviews. Verbal consent was confirmed prior to all interviews. Figure 10, on the next page, is a flow chart outlining subsequent interviews.

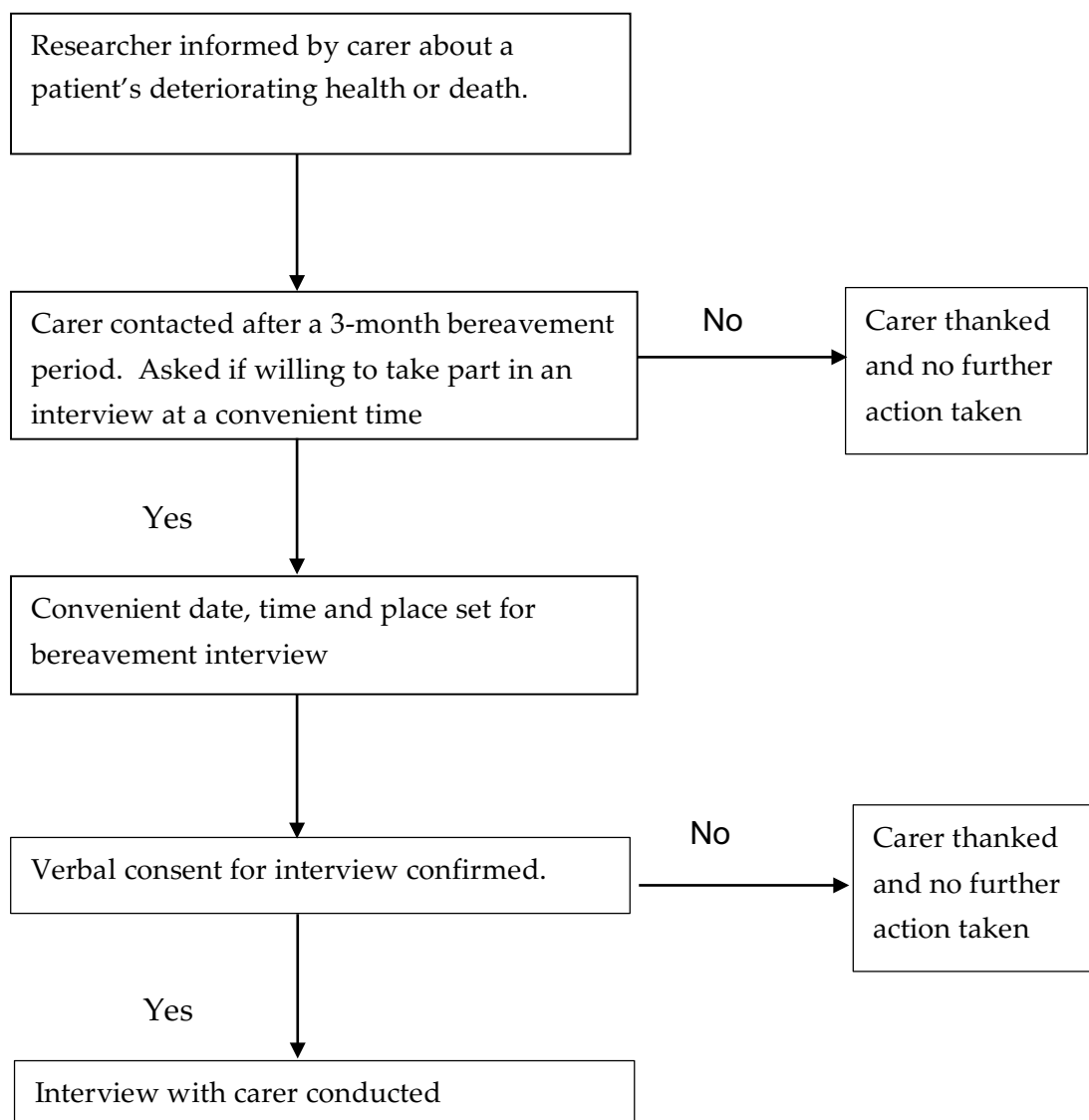
**Figure 10:** Subsequent patient interviews flow chart



### 3.4.2 Bereavement interviews

Bereavement interviews were held with carers of patients who died before the end of the study period. These interviews offered insights into patients' experiences during their last days of life. Once notified of a patient's death (during monthly phone calls), interviews were scheduled after allowing for a culturally appropriate bereavement period of 3 months. Figure 11 below is a flow chart of bereavement interviews with carers.

**Figure 11:** Bereaved carer interview flow chart



### **3.4.3 Field notes**

Field notes are an established method of recording observed data in longitudinal studies (Ritchie et al., 2014:171-172). They are products of an active process of meaning making (Emerson et al., 2011:9). They provide descriptions, commentaries and reflections about events and ideas which emerge during fieldwork (Braun and Clarke, 2013:330). For this study, notes about the research context, observations made during interviews, methodological concerns and data analysis were recorded. Field notes were also used to summarize and organise thoughts and reflections emerging from an interview. Field notes were written within twenty-four hours after conducting an interview. Appendix 18 is a sample of field notes recorded after the first interview with the first patient recruited for this study.

## **3.5 Data management**

All interviews were conducted and audio-recorded in the local language Kiswahili, and transcribed into English. After each interview, audio files were downloaded onto a password-protected computer, which was only accessible to the researcher. To maintain confidentiality and anonymity, data capable of revealing the identity of a participant (recruitment forms and consent forms) were stored securely in a locked filing cabinet. These forms were separate from other sources of data including field notes, transcripts and audio-recordings. Audio recordings did not include any participant identifiable data.

Audio recordings were transcribed verbatim in English, and changes in intonation were also noted. The researcher and participants spoke the same language, which may have helped to minimise loss of meaning while



transcribing. However, in interpreting spoken Kiswahili to English, some meaning may have been lost. To limit the extent in which meaning could be lost, transcripts were repeatedly reviewed against audio-recordings to ensure that translations remained true to the source language. Additionally, an assistant with experience in Kiswahili-English translation and transcription provided assistance in transcribing audio files to English (van Nes et al., 2010). Regular debriefing sessions were held to mitigate against emotional risk from translating sensitive information.

### **3.6 Data analysis**

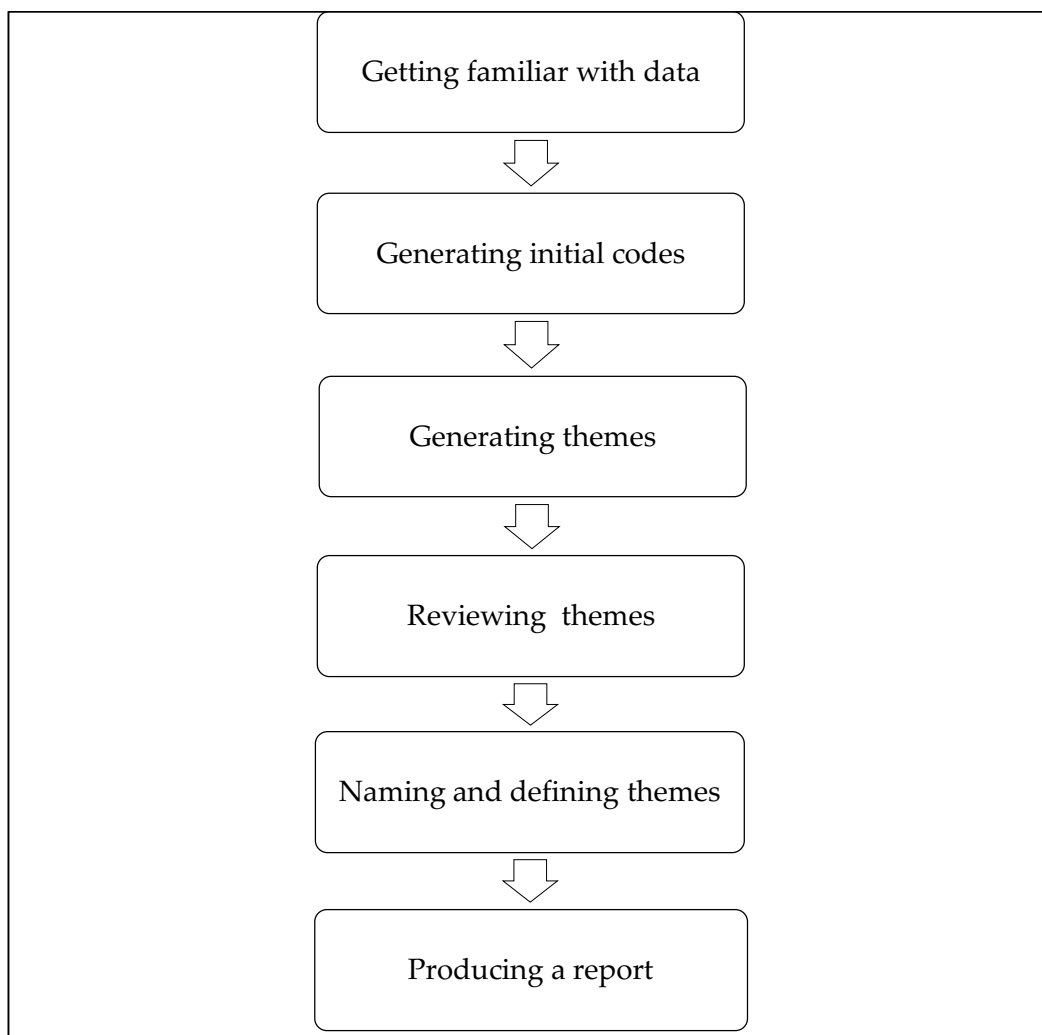
Qualitative data analysis is an evolving process which starts at the conception of a research project and comes to an end at the report writing stage (Ritchie et al., 2014:275). Approaches to qualitative data analysis are numerous and diverse. Substantive techniques such as thematic analysis aim to understand and make interpretations of meanings within qualitative data. These techniques view data as windows opening into people's social world to reveal their views, feelings, beliefs and attitudes towards a topic of study. On the other hand, structural approaches such as discourse, conversation analysis, and narrative analysis emphasize analysing the structure of talk, text or language to understand how meaning is constructed. Other methods such as grounded theory attempt to develop theory from qualitative data (Ritchie et al., 2014:272 ; Braun and Clarke, 2013:174). Commonly, analytical approaches are linked to specific academic disciplines and are based on underlying philosophical assumptions guiding the research process (Crotty, 1998:2).

Given the extensive range of analytical approaches to qualitative research, selection of an appropriate technique should be guided by underpinning philosophical assumptions, the nature of the research, aims of a study and the level of experience with qualitative research (Ritchie et al., 2014:272).

For this study, several approaches were considered while selecting an appropriate data analysis technique. These included thematic analysis, grounded theory, narrative analysis and discourse analysis. Selection of a suitable method was guided by the aims of the research, the researcher's philosophical assumptions, and experience in undertaking qualitative research. Due to its flexibility, thematic analysis was chosen as the preferred method for data analysis. Thematic analysis has been applied in qualitative studies in sociology, psychology and in longitudinal research exploring the experience of living with chronic illness (Earle and Eiser, 2007 ; Tuchman et al., 2008 ; Braun and Clarke, 2013:178). Thematic analysis is a substantive technique that focuses on exploring people's experiences, beliefs and views which aligns with the aim of this research. Furthermore, most approaches to qualitative analysis include a stage of thematic coding, and thematic analysis may be appropriate to those new to qualitative research as it supports learning of how to handle and code data (Braun and Clarke, 2013:178).

Data analysis was guided by Braun and Clarke's (2006) approach to thematic analysis which identifies six key stages: data familiarisation, generating codes, generating themes, reviewing themes, naming and redefining themes and producing a report (Figure 12 overleaf). Each stage is discussed in the following section.

**Figure 12:** Stages in thematic analysis. Source: Braun, V. & Clarke, V.(2006)



### **Stage 1 – Familiarisation**

The aim of this stage was to understand the width and breadth of the data and identify key issues and topics relevant to the research. Each transcript was read actively asking 'how are participants making sense of their experience?' (Braun and Clarke, 2013:205). After this initial reading, the transcript was broken down into sections corresponding to key issues explored in the topic guide. Memos were used to note interpretations and patterns identified in the data. These were recorded directly on each

transcript. After this initial reading, transcripts were imported into Nvivo qualitative data analysis software (QSR International Pty Ltd ,2012) in preparation for coding.

### **Stage 2 – Generating initial codes**

This stage involved identifying aspects of data that were relevant to answering the research questions. Codes were generated in two ways: (i) inductively which allowed ideas and concepts to emerge from the data and (ii) deductively which identified codes that have been mentioned in previous research. Appendix 19 is a list of codes generated for the first set of interviews

### **Stage 3 - Generating themes**

Codes identified in stage 2 were further examined to identify potential patterns which could be collated into a theme (central organising concept) or sub-themes. Themes and subthemes were arranged in hierarchy. Themes described salient features of the data relevant to answering the research questions and sub-themes offered a lower explanation of a theme (Braun and Clarke, 2013:225). These were reviewed cross-sectionally with each set of interviews and longitudinally along the three set of interviews. All themes and subthemes identified at this stage were preliminary and were refined in subsequent stages. Appendix 20 shows initial themes and sub-themes identified during data analysis

### **Stage 4 - Reviewing themes**

This stage involved refining preliminary themes and subthemes to make sure they cohered with the coded data and the entire data set. To ensure coherence with coded data, themes and subthemes were re-examined to make certain they were a faithful representation of coded data. Coded data

were re-organised by collapsing some themes into others or developing and renaming new themes and sub-themes. A final re-reading of the dataset was done to ensure themes captured the essence of the entire data set.

### **Stage 5 - Naming and defining themes**

Each theme was reviewed to identify its focus, purpose and define what it was about. Each theme told a story that would fit into the broader narrative of the data set.

### **Stage 6 – Producing a report**

At this stage, quotes from the data were used to illustrate the essence of a theme. Rich and vivid extracts from the data were identified to act as evidence in support of the story in each theme or subtheme. Extracts were drawn from cases across the data set to illustrate the extensiveness of a theme. These themes are presented in Chapters 5-7.

## **3.7 Rigour**

In accessing rigour, Lincoln and Guba (1985) propose that the fundamental question a researcher should ask is 'how can an inquirer persuade an audience that the finding of an inquiry are worth paying attention to, worth taking account of?' (Lincoln and Guba, 1985:290). The following four criteria were used to judge the rigour of this research.

### **Credibility**

This refers to how well the research findings represent the data. A reflexive journal and regular debriefing sessions with supervisors and peers were helpful strategies to uncover biases that might have been introduced in the research. Having audio recordings allowed continued engagement with the

data and provided the researcher with an opportunity to go back and review information and check emerging themes. Using thick descriptive quotes helps readers of this research to judge whether the findings are an accurate representation of participants' accounts (Noble and Smith, 2015 ; Houghton et al., 2013).

### **Transferability**

This refers to whether the results of a study can be applied in other contexts. To support transferability, data on the demographic characteristics of participants were collected and described. These results are presented in Chapter 4. Furthermore, a description of the context in which this research was conducted was provided (Chapter 1) to help readers judge the applicability of this research to other settings (Thomas and Magilvy, 2011 ; Noble and Smith, 2015).

### **Dependability**

Dependability makes reference to the stability of data and is confirmed by an audit trail. In the course of this project, a research diary was kept to document changes and issues arising. Additionally, this thesis provides a description of methodology, methods, data generation procedures, data analysis, and results which enhances the transparency and reproducibility of this research (Houghton et al., 2013 ; Thomas and Magilvy, 2011 ; Noble and Smith, 2015).

### **Confirmability**

Confirmability is established by making certain credibility, transferability and dependability is achieved. It requires reflexivity and centres on a researcher acknowledging the complexities of engaging with the research

and with participant accounts. Chapter 9 supports the confirmability of this research by reflecting on the challenges posed by this study and how they may have influenced the research process (Noble and Smith, 2015).

### **3.8 Ethical Issues**

Ethics is an important principle governing how we relate to participants, institutions, and the society where we carry out our research (Braun and Clarke, 2013:61). Ethics is an important component of all stages of research and does not only refer to following standards as set in codes of conduct. (Creswell, 2007:55). Guillemin and Gillam (2004) describe two approaches to ethics in qualitative research (i) procedural ethics which includes approval from institutional ethics committees and (ii) ethics in practice which includes ethical issues encountered in the day to day process of conducting research.

#### **3.8.1 Procedural ethics**

Before conducting fieldwork, ethical approval was obtained from the University of Edinburgh (CPHS Research Governance) (Appendix 21) and the Kenyatta National Hospital/University of Nairobi Ethics and Research Committees in Kenya (Appendix 22). Additionally, permission to collect data was sought from hospital management at Kiambu District Hospital in Kenya. (Appendix 23)

### **3.8.2 Ethics in practice**

#### **Informed consent**

Good research practice requires potential participants to be adequately informed before they make a decision on participation (Webster et al., 2014). Before deciding to take part, participants were informed of the study's purpose, aims, procedures, benefits, and risks. It was also explained that their participation was voluntary and that if they wished, they could withdraw at any time. Details of how confidentiality would be maintained and the study's expected outcomes were disclosed.

When a potential participant agreed to take part, they were asked to provide written and signed or a thumbprint confirmation of their decision prior to the first interview. Patients were asked to give permission for the researcher to phone monthly to review progress, review medical records, approach their choice of carer for interviewing, use anonymised quotes in publications, and data in secondary analysis. Carers were also asked to consent to the use of anonymised quotes in publications and permission to use data in secondary analysis (Appendix 6-9;14-17)

#### **Anonymity and confidentiality**

To ensure anonymity and confidentiality, the true identity of every participant was concealed. Participants' names on transcripts and field notes were anonymised and replaced with pseudonyms. Any data with a potential of revealing the true identity of a participant was filed separately and securely.



## **Reciprocity**

By agreeing to take part in research, participants take time away from their normal activities including work and family responsibilities. In return, a researcher may feel the need to give participants a token to acknowledge their contribution to the research process (Dickson-Swift et al., 2007). An appropriate token should promote the development of trusting relationships between study participants and the researcher. It should also be culturally sensitive and acceptable to participants (Ellis and Earley, 2006). For this study, a culturally sensitive token of groceries (sugar, rice, maize flour or milk) worth Ksh 500 (£3) was offered to all participants at each interview. For interviews conducted in the hospital ward, a shopping voucher of similar value was provided for participants to purchase groceries after discharge from hospital.

### **3.8.3 Risks in research**

#### **Risks to participants**

Patients with heart failure are considered a vulnerable population because of the premature mortality associated with their illness (Flaskerud and Winslow, 1998). They are also at risk of emotional distress after sharing sensitive information. Similarly, carers may suffer from emotional stress after the death of their loved one. Cognizant of the risks this research posed to participants, the following precautions were taken (McCosker et al., 2001).

All participants were offered the opportunity to select a suitable time and place for each interview. This ensured that they felt safe and comfortable to take part in the study. Before each interview, participants were reminded of the aims of the research and were made aware that their contribution was

voluntary. Additionally, interviews only commenced after participants confirmed verbal consent.

During the interview, participants were also encouraged to share only what they were comfortable disclosing. In the event a participant became distressed, the interview was stopped immediately, and the audio-recorder switched off. The interview resumed only when a participant felt ready to do so. Principles of anonymity and confidentiality were adhered to at all stages of the research.

### **Risks to the researcher**

While conducting this research, the following risks were acknowledged.

Conducting interviews at a time and place that was convenient for study participants presented a physical risk to the researcher. To mitigate potential physical harm, a male colleague accompanied the researcher to the place of interview. However, confidentiality was maintained as he did not sit in for the interviews. Moreover, the vulnerable nature of this research exposed the researcher to emotional harm. Emotional exhaustion from listening to participants' experiences over a prolonged period was also a significant risk. Throughout the study, the option to speak to a counsellor was made available. Regular debriefing with colleagues was helpful in discussing difficult issues and aided reflexivity. This research also posed a financial risk as some participants may have expected monetary assistance with medical care, funeral costs other household expenses. A small fund was set up to assist with these costs when a need arose. The implications of these risks are discussed further in Chapter 9.

Although it was not possible to identify all the potential risks while conducting this research, regular meetings were held with the supervisory team to identify and review unforeseen risks.

### **3.9 Reflexivity**

Denzin and Lincoln (2005:210) define reflexivity' as the process of critically examining the self as a researcher, the human as an instrument.' In qualitative research, the researcher is actively involved in generating, analyzing and interpreting data. Indeed, the researcher participates in data co-production with participants, and is part of the social world in which research is conducted. In this case total objectivity is unattainable and data analysis becomes an interpretive process in which meaning is made when interacting with data rather than being found (Mauthner et al., 1998) (Mauthner et al., 1998 ; Ahern, 1999).

The role of reflexivity is to support the interpretation of research findings and offer unique insights of the research experience. Meanings are constructed in particular social contexts and it can be expected that another researcher undertaking similar research will unfold different findings. (Finlay, 2002). Personal beliefs, assumptions and subjectivities are likely to influence the way in which research is interpreted. Being reflexive helps a researcher become aware of how personal subjectivities may enhance how research is conducted and the accuracy of its findings (Berger, 2013). Therefore reflexivity not only supports transparency and trustworthiness but also the ethical conduct of research (Guillemin and Gillam, 2004).

The term 'reflexivity' and 'reflection' are often confused and thought to be interchangeable. Finlay (2008:7) suggests that it is helpful to think of

‘reflection’ and ‘reflexivity’ as opposite ends along a continuum. Reflection can be explained as thinking about something after an event has occurred while reflexivity is a dynamic process of self-awareness.

The following section provides a reflexive account of how my personal biographies as well as how being an insider/outsider may have influenced this research. I have chosen to discuss my status as an insider/outsider to describe the instances in which my personal traits may have aligned or separated me from the community under study. This section is written in first person to reflect subjectivity.

### **Why this research**

It is important for a researcher to be aware of their motives for conducting research that may influence the trustworthiness of a project (Watt, 2007). In hindsight, the topic of my doctoral research was influenced by my personal and professional biographies. Before beginning my Ph.D. research, I worked as a medical doctor at a busy public hospital. At the time, the disease burden from infectious diseases and maternal and child health conditions was high and local health policies were directed towards caring for patients with these conditions. While these efforts were helpful in addressing urgent population needs, they turned attention away from an increasing chronic disease burden.

Most patients with heart failure who received care at the hospital were already in the advanced stages of illness. Treatment goals focussed on symptom control with little attention to other dimensions of care. At the time, personal experience with chronic illness had taught me that there is more to illness than physical symptoms. I was drawn to patients’ stories and

motivated by my experience to want to understand how we can improve care to identify and meet patients' needs beyond physical symptoms.

#### Being an insider and an outsider

Certain personal characteristics made me a member of the community I was studying while others created distance between me and the characteristics the community shared. As an insider, I shared a similar nationality, ethnicity and religious faith with most participants. All participants were Kenyan nationals, most were from the Kikuyu ethnic group, and majority professed a christian faith. These characteristics may have eased my engagement with participants to feel comfortable with telling their stories since we had shared a common understanding of the social, religious and cultural context in which their illness occurred (Berger, 2013). However, familiarity with the context may have introduced potential bias. For example, I may have been less sensitive to patients with unique experiences including those with stories much different from those regarded as common in the context in which the research was conducted.

At the hospital, I had an insider status. I had previously worked with some of the doctors at the hospital and this shared experience helped in accessing potential patients for recruitment (Merriam et al., 2001). Having an insider status at the recruiting facility may have led doctors and nurses to introduce me in a way that insinuated that I was part of the treatment team. Although I never revealed my real identity (as a medical doctor) most participants thought I was involved in their care. The fact that their doctor/nurse introduced me in the ward and it was mentioned that I was interested in finding out about their illness, led some patients to believe that I was part of their treatment team. Patients may have chosen to focus on their physical issues believing that the research was interested in addressing their physical

symptoms at the expense of other multidimensional concerns. On occasion, patients would call to ask for advice on treatment not only for themselves but also for their family members. While I was not in a position to offer medical advice, I referred patients to seek help from their primary health professional.

In addition, my age and gender also conferred an insider and an outsider status. Most participants aged on average 50 years with a few in their 30s and 60-70s. Patients in their 30s were easier to relate to, since we were of similar age and I identified more with their experiences. However, this was not the case with older patients, who because of our age differences regarded me as their 'daughter', and were not willing to disclose sensitive issues as they felt it would be inappropriate to share these with a young person. I also found that I related better with women and developed relationships that fostered the exploration of personal issues. However, older men (40 years and above) were less eager to discuss their more sensitive concerns, more so with a younger woman, and may have viewed such discussions as culturally inappropriate. In this context, older people are assigned a higher social status than younger people. This may have created a power dynamic between me and older participants (especially male participants) which limited the extent in which we could discuss more sensitive issues of their illness experience (Merriam et al., 2001).

### **3.10 Chapter Summary**

This chapter described the methodologies and methods informing this research. It outlined the recruitment of participants and how data was generated and managed. It concluded with a section on reflexivity

The next chapters (4-7) details the findings of this research. Chapter 4 describes the participants recruited for this study and interviews conducted while Chapters 5-7 present themes and subthemes illustrating the experiences of patients living and dying with heart failure in Kenya.

## **Chapter 4 : Participants and interviews**

Due to the intricate nature of longitudinal qualitative research, this chapter aims to summarize participants' characteristics and interviews conducted.

### **4.1 Participants**

#### **4.1.1 Patients who agreed to participate**

Fifty-three patients were approached to take part in this study. Twenty agreed to participate, twenty-two declined, and eleven were on further review, found unsuitable for recruitment.

For the twenty patients (11 female; 9 male) who agreed to take part, their age ranged 19-75 years (median 50 years) (Table 4, next page). Twelve patients had primary school or lower level of education. More than half (12 out of 20) were diagnosed with hypertensive heart disease (HHD) as a cause of heart failure. Other common causes were: right sided heart failure (RHF) from chronic obstructive pulmonary disease (COPD; n=4) and dilated cardiomyopathy (DCM; n= 3). For one patient the cause of heart failure was unknown. All patients had advanced heart failure (NYHA III = 12; NYHA IV = 8). Eleven patients had comorbid conditions, with diabetes (n=4) and COPD (n=4) being the most common.

By the end of the study, five patients had died, and four were deemed untraceable after multiple and unsuccessful attempts to re-establish contact over mobile phone.



**Table 4:** Participant characteristics (\*fictional names assigned to preserve anonymity)

No.	Name*	Age (years)	Sex	Level of Education	Aetiology	NYHA class	Co morbidity	Carer	Interview dates (DD/MM/YY)			Bereavement interview conducted
									T1	T2	T3	
1.	Shiru	57	F	Tertiary	Hypertensive heart disease	III	Diabetes Mellitus	sister-in law	4/12/14	4/3/15	25/6/15	
2	Wangu	35	F	Primary	Hypertensive heart disease	IV	Diabetes Mellitus/ HIV	son	11/12/14	10/2/15	23/6/15	
3.	Jaba	65	M	Secondary	Dilated cardiomyopathy	IV	-	brother	7/1/15	4/4/15	13/7/15	
4.	Samueli	75	M	Informal	Right sided heart failure	III	COPD	daughter	13/1/15	17/4/15	16/7/15	
5.	Njenga	31	M	Primary	Right sided heart failure	IV	COPD/Lung fibrosis from previous tuberculosis	uncle	23/1/15	11/2/15	4/8/15	
6.	Chera	60	F	Primary	Hypertensive heart disease	IV	Renal failure	daughter	28/1/15	DIED 5/3/15		Yes 15/6/15
7.	Mbui	50	M	Tertiary	Dilated cardiomyopathy	III	-	Friend (male)	4/2/15	17/5/15	18/9/15	
8.	Ruguru	50	F	Secondary	Hypertensive heart disease	III	-	daughter	28/2/15	12/6/15	22/9/15	
9.	Riro	38	M	Secondary	Hypertensive heart disease	III	-	mother	7/3/15	Untraceable		
10.	Cege	45	M	Primary	Right sided heart failure	IV	COPD	cousin (female)	9/3/15	16/6/15	DIED 3/8/15	No - Carer lives beyond 35 km radius

COPD – Chronic obstructive pulmonary disease; HIV – Human immunodeficiency virus, T1 = 1<sup>st</sup> interview ; T2= 2<sup>nd</sup> interview ; T3 = 3<sup>rd</sup> interview

**Table 4:** Participant characteristics (continued) (\*fictional names assigned to preserve anonymity )

No	Name*	Age	Sex	Level of Education	Aetiology	NYH A class	Co morbidity	Carer	Interview dates (DD/MM/YY)			Bereavement interviews
									T1	T2	T3	
11.	Nanjala	50	F	Primary	Hypertensive heart disease	III	-	husband	16/3/15	2/6/15	24/9/15	
12.	Bui	19	F	Secondary	Unknown	IV	Extrapulmonary tuberculosis	father	25/3/15	2/7/15	15/10/15	
13.	Irungu	60	M	Secondary	Hypertensive heart disease	III	Diabetes	wife	23/4/15	30/7/15	22/10/15	
14.	Njambi	60	F	Primary	Hypertensive heart disease/Myocardial infarction	IV	Asthma	daughter	28/4/15	DIED 16/5/15		Yes 29/8/15
15.	Nyambu	31	F	Secondary	Dilated cardiomyopathy	III	-	husband	26/5/15	Untraceable		
16.	Waithera	33	F	Primary	Hypertensive heart disease	III	-	sister	1/6/15	6/9/15	4/12/15	
17.	Mutengo	81	M	Primary	Hypertensive heart disease	III	-	none	DIED 27/5/15			
18.	Muthoni	50	F	Primary	Hypertensive heart disease /Angina	III	Diabetes	daughter	24/7/15	23/10/15	Untraceable	
19.	Awina	57	F	Primary	Hypertensive heart disease	III	-	daughter	DIED 23/7/15			
20.	Jamo	36	M	Primary	Right sided heart failure	IV	COPD	Friend (male)	9/9/15	Untraceable		

COPD – Chronic obstructive pulmonary disease; HIV – Human immunodeficiency virus; RIP – Rest in peace, T1 = 1st interview ; T2=2<sup>nd</sup> interview ; T3=3<sup>rd</sup> interview

#### **4.1.2 Patients who declined participation**

Table 5 overleaf summarizes characteristics of patients who declined to participate.

Out of the 22 patients (11 female; 11 male) who declined to participate, nine had hypertensive heart disease as the cause of heart failure. Other common causes were COPD (n=4) and cardiomyopathy (n=4). Their ages ranged 25-80 years (median 51 years) and more than half (13 out of 22) had achieved primary or lower level of education.

Twelve patients did not give a reason for deciding not to participate. For those who gave reasons, some patients chose not to participate because they were not aware of their diagnosis (n=2) or wanted to get better first (n=2). Others did not believe they had heart failure especially once their acute symptoms resolved (n=1); felt they had no experience of the illness and could not contribute to the study (n=1); preferred a phone interview rather than a face to face interview (n=1); had problems accepting their diagnosis (n=1), had other commitments (n=1) or could not participate for religious reasons (n=1; a Muslim patient fasting during Ramadhan).

All of these patients communicated their decision of not wanting to participate after the ward doctor/nurse informed them about the study and after they received a copy of the patient information sheet and consent form.

**Table 5:** *Anonymised details of patients approached but declined to participate*

Participant number	Aetiology of heart failure	Age Years	Sex	Level of education	Reasons for declining
1	Dilated cardiomyopathy	30	M	Primary	Not aware of diagnosis.
2	Not confirmed	35	F	Secondary	Did not believe she had heart failure
3	Cardiomyopathy	25	F	Secondary	No reason given
4	Hypertensive heart disease	46	M	Secondary	Believed he did not have enough experience with illness
5	Not yet confirmed	80	M	Primary	Wanted to get better before taking part
6	Right sided heart failure	79	M	Primary	No reason given
7	Right sided heart failure	47	M	Primary	No reason given
8	Hypertensive heart disease	56	M	Secondary	Traveling to rural home
9	Dilated cardiomyopathy	40	M	Primary	No reason given
10	Hypertensive heart disease	73	F	Primary	No reason given
11	Hypertensive heart disease	38	F	Secondary	Preferred a phone interview
12	Hypertensive heart disease	74	M	Secondary	Wanted to get better before participating
13	Hypertensive heart disease	56	F	Primary	No reason given
14	Right sided heart failure	36	F	Secondary	No reason given
15	Right sided heart failure	53	M	Secondary	Not aware of diagnosis
16	Not confirmed	65	M	Primary	Observing Ramadhan
17	Not confirmed	63	F	Primary	No reason given
18	HIV/Not confirmed	48	F	Secondary	No reason given
19	Hypertensive heart disease	56	F	Informal	No reason given
20	Alcoholic cardiomyopathy	46	M	Primary	No reason given
21	Hypertensive heart disease	66	F	Primary	Had not accepted her diagnosis
22	Hypertensive heart disease	45	F	Primary	No reason given

### **4.1.3 Patients found unsuitable for recruitment**

Eleven patients were found unsuitable for recruitment after reviewing their eligibility. This was after they had been introduced to the study, received a copy of patient information sheet and consent form and their details passed on to the researcher. They were found unsuitable for inclusion due to: declining cognitive capacity (7), lived 35 km beyond hospital (3) and not having advanced heart failure (stage III or IV) (n=1).

### **4.1.4 Carers**

Nineteen patients chose to nominate a carer to be interviewed. Seventeen of these carers were either nuclear or extended family members. For two patients a friend acted as a carer. Eleven carers were female, and eight were male (Table 4). Nearly all carers (n=18) lived with or close to patients. Only one carer lived beyond the 35km recruiting radius.

Of the five patients who died in the course of the study, two bereavement interviews were conducted. The remaining bereavement interviews were not held because one carer lived 35km beyond the hospital and the other two carers were untraceable.

## **4.2 Interviews**

### **First interview**

Out of twenty patients who agreed to participate, eighteen took part in the first set of interviews. Eleven of these were conducted in a side room in the ward, six were at home and one was at a restaurant.

## **Second interview**

The second set of interviews were planned to take place three months after the first interview. Patients were phoned 1-2 weeks prior to the second interview to arrange a convenient time and place for an interview.

Of the eighteen patients who participated in the first interviews, thirteen took part in the second set of interviews. By this time two patients had passed away, and three were deemed untraceable after several unsuccessful attempts to establish mobile phone contact with them or their carer. Nine interviews took place at home, two were in the ward and two were held at a restaurant.

Out of these 13 interviews, 10 were conducted three months after the 1<sup>st</sup> interview, two were flexible and took place before the date planned for the second interview, and one was conducted four months after the 1<sup>st</sup> interview. For the flexible interviews, one took place three weeks and the other two months after the 1<sup>st</sup> interview (patient 5 and patient 2 respectively). In both cases, the patient was readmitted with an acute episode, and an earlier interview was scheduled to document circumstances triggering a readmission. For the interview conducted four months (patient 8) after the first interview, patient and carer were untraceable as they did not have access to a mobile phone at the time (Table 4).

## **Third interview**

Out of 13 patients who participated in the second interviews, 11 took part in the third set of interviews. By this time, another patient had died (patient 10) and one was untraceable (patient 18). Eight of these

interviews were conducted at home and three at a restaurant. Nine interviews were conducted on time. Two interviews were delayed: one patient (patient 7) could not be contacted by mobile phone in time for the third interview. The interview was carried out one month later. The second patient (patient 2) had the third interview delayed by a month as she was not well enough for an interview after a hospital readmission (Table 4).

### **Bereavement interviews**

Five patients died in the course of the study (patients 6, 10, 14, 17, and 19). Patient 17 and 19 died on the ward before the first interview and were yet to nominate a carer. Patient 6 and 14 died after the first interview and patient 10 after the second interview. Bereavement interviews were carried out for patient 6 (with daughter) and patient 14 (with daughter). Patient ten had identified a carer (cousin) to be interviewed. However, the carer lived outside the recruiting radius and was not interviewed. The participant was given the option of choosing another carer who lived close by but declined as his preferred carer was the person most likely to offer him financial help (Table 4).

### **Monthly mobile phone calls**

All patients were phoned once a month in between interviews to follow up on their condition, arrange for subsequent interviews, and maintain contact. Twelve patients owned a mobile phone, and the rest were reachable through their carer. Monthly call logs were kept to record key observations made during each phone call.

### **4.3 Chapter Summary**

This chapter described the characteristics of participants and interviews conducted. Specifically, it detailed the sociodemographic and clinical details of patients who agreed to take part and the anonymised details of those who declined to participate. Both groups shared similarities in age, causes of heart failure and level of education attained. This chapter also outlined interviews conducted, including bereavement interviews, and monthly mobile phone calls. The next chapter presents the research findings.



## Chapter 5 : Patients' experience of heart failure

This chapter presents experiences of heart failure as described by patients and their bereaved carers. Three key phases were identified as part of their illness journey: (i) coming to a diagnosis (ii) living with heart failure and (iii) dying with heart failure. A detailed account of each phase is provided below.

### 5.1 Coming to a diagnosis

#### How it all began

Most patients could recall how their illness started. They described their experience with multiple physical symptoms such as breathlessness, fatigue, swelling of ankles and feet, cough and palpitations. Breathlessness was the most recognised symptom but its onset and severity varied. For some patients, the onset of breathlessness was sudden and often unexpected.

It started with breathlessness. I could not breathe at all....it was a like an (asthma) attack. I had to leave the house immediately and go to the hospital... I could sense danger. *[Ndungu, 50, male, 1<sup>st</sup> interview, dilated cardiomyopathy (DCM)]*

For others the onset of breathlessness (and other symptoms) was gradual and often went unnoticed. Patients normalised symptoms and located them in activities of daily life.

I thought I was breathless because of the hills I was climbing on my way home. I was breathless for years. *(Cege, 45, male, 1<sup>st</sup> interview right sided heart failure' [RHF] from COPD)*

When I first noticed that my feet were swollen I thought that maybe it was caused by sitting close to the 'jiko' (charcoal stove) while cooking. *[Nanjala, 50, female, 1<sup>st</sup> interview, Hypertensive heart disease (HHD)]*

However, in some cases patients went back in time and narrated how symptoms began after they were diagnosed with other chronic diseases. Although heart failure was described as a separate illness, its onset was linked to these conditions.

This problem of mine (heart failure)... it started when I had headaches and fatigue...when I was diagnosed with 'pressure' (hypertension).  
*(Shiru, 57, female, 1<sup>st</sup> interview, HHD/diabetes)*

It (heart failure) started with a lot of pain in the chest pain. My left arm was also numb. I was told that my heart was blocked with fat. I was breathless. *(Muthoni, 50, female, 1<sup>st</sup> interview, HHD, diabetes, angina)*

Others described how they thought their illness began like an 'ordinary illness' or 'ugonjwa ya kawaida' (local language). This was in reference to non-specific symptoms such as fatigue which patients thought were caused by common conditions they had experienced in the past.

I thought it was an ordinary illness like malaria or pneumonia because when you have malaria you do not feel like doing much. When you have pneumonia, you might feel breathless. *(Riro, 36, male, 1<sup>st</sup> interview, RHF/COPD)*

This illness started slowly. I thought it was normal and caused by anaemia. I was treating myself. It is not every time I would go to the hospital because I knew the drugs to take. *(Ruguru, 50, female, 1<sup>st</sup> interview, HHD)*

## **Seeking care**

Patients described how their symptoms began to limit their day-to-day life. For most patients worsening breathlessness, especially with increased physical activity, was the main trigger for seeking care.

I would get breathless after walking short distances and would need to stop to catch my breath....it was a strange illness. That is when I decided to go to the hospital. *(Jamo, 36, male, 1<sup>st</sup> interview, RHF/COPD)*

Patients sought care at the nearest health facility that would offer immediate relief for their symptoms. The decision of when to seek care was made in consultation with family or friends.

It started with breathlessness ... I had trouble walking from here to there. I told my children the illness had 'defeated' me. They discussed it and arranged to take me to the hospital. (*Samueli, 75, male, 1<sup>st</sup> interview, RHF with COPD*)

I was breathless after walking short distances. I went to a nearby private clinic for treatment but I was not getting better....my friend advised me to return to the hospital. She even came along with me. (*Nanjala, 50, female, 1<sup>st</sup> interview, HHD*)

Some patients spoke of the challenges they faced getting to the hospital especially when they needed emergency care. Those who were living alone had a greater challenge as they had no one to help them arrange transportation. Ndungu, a single middle-aged man who likened his symptoms to an 'asthmatic attack,' described his experience of getting to a hospital during an acute episode.

I could not breathe at all and I was living alone. It was around 1am....it was New Year's Eve and I could not get anyone to take me to the hospital. Luckily, a motorcycle passed by but at that time I was fatigued and fell to the ground. The man on the motorbike thought I was drunk but I was gasping for air. I tried to convince him I was ill. He wanted to drive away but I held on to the rear wheel of his motorbike. That is when he realized I was ill and took me to the hospital. (*Ndungu, 50, male, 1<sup>st</sup> interview, DCM*)

## **Receiving a diagnosis**

Nine patients described the difficulty they encountered in establishing a diagnosis of heart failure. Patients, particularly those who were younger, were initially treated for common conditions such as malaria, pneumonia, tuberculosis and asthma. Non-specific symptoms such as fatigue, lethargy,

cough and chest pain made it challenging to distinguish between a treatable acute illness and a more serious life-threatening condition. For Jaba and Waithera, heart failure was a diagnosis of exclusion.

I was diagnosed with pneumonia although at times it did not seem like pneumonia. I have been treated for pneumonia 3 times. The doctor who was treating me told me he would not treat me for pneumonia again. He sent me to get a an x-ray of my heart. (*Jaba, 65, male, 1<sup>st</sup> interview, DCM*)

I was breathless, I could not breathe. I was on oxygen...They said it was asthma. The next day they told me it was not asthma. They said my heart has a problem. (*Waithera, 33, female, 1<sup>st</sup> interview, HHD*)

For other patients, especially those who were older and were already receiving treatment for other chronic conditions, a diagnosis of heart failure was made earlier. Some recounted how they were already on treatment for diabetes or hypertension before receiving a diagnosis of heart failure. Diagnosis of a common co-morbid chronic illness made the diagnosis of heart failure easier. (*Field notes Irungu, 60 male, 1<sup>st</sup> interview, HHD, diabetes*).

## **5.2 Living with heart failure**

Once a diagnosis of heart failure was confirmed, patients came face to face with physical, social, financial, psychological and spiritual issues. The next section explores the multidimensional experience of living with heart failure.

### **Physical issues**

Soon after starting their treatment, some patients felt relieved that their symptoms had subsided and mistook this to mean that they were healing.

I do not think I have a heart problem now. It is not like the last time....that was a bad time. I could not sleep....I was uncomfortable. I am doing much better. (*Ruguru, 50, female, 2<sup>nd</sup> interview, HHD*)

I am doing okay...my body is okay and I do not have any problem. I am taking my medication and the heart problem I had...I do not have it anymore. Since I left hospital...I feel okay. (*Jaba, 65, male, 2<sup>nd</sup> interview, DCM*)

Patients were hopeful that an improvement in symptoms meant that they could get back to their lives and take part in the activities they previously enjoyed. Nanjala spoke of how she was able to attend a weekly church service.

My heart used to beat really hard but now not as much. There are times I was not able to attend church. However, for the past two Sundays I have been to church. Now I have no problem walking uphill and downhill on my way to church. (*Nanjala, 50, female, 2<sup>nd</sup> interview, HHD*)

Others, however, expressed their frustration of living with a progressive and persisting illness. Patients were disappointed and bewildered by an illness not responding to treatment. These feelings intensified in patients with frequent hospital visits and readmissions. Shiru explained why she preferred a diagnosis of AIDS.

Why only me? Why did I get this illness? Maybe I should have had AIDS. At least with AIDS there is medication and you can get back to work. But this illness does not get better. (*Shiru, 57, female, 3<sup>rd</sup> interview, HHD/diabetes*)

## **Social issues**

Most patients appreciated the concern they received from family and friends. Some patients spoke of how the support they received helped in easing their distress.

My family supports me. My daughter calls me every other day. My son also phones me to find out how I am. I am happy because my children remember me. *(Irungu, 60 male, 1<sup>st</sup> interview, HHD/diabetes)*

Some of my friends come to visit and they encourage me to remain positive. They do not want me to worry. *(Nanjala, 50, female, 2<sup>nd</sup> interview, HHD)*

Support was not limited to friends and family. One participant shared how her workmates allowed her time off so she could rest at home.

When I call my boss he asks me if I am taking my medication. He says I should continue my treatment and he will call me when they need me at work. Whenever I go to the office, my workmates tell me not to worry because they will take care of my duties. *(Shiru, 57, female, 2<sup>nd</sup> interview, HHD/diabetes)*

However, other patients described how the long-term nature of their illness brought tension to social relationships. Several patients shared how family and friends withdrew over time.

Sometimes illness can cause a big separation in the family. When I am unwell, my father is not helpful. He has left us on our own and I have to take care of my mother. Before I fell ill, I had a good relationship with my father. Right now he is not happy with me because the hospital bill needs to be paid and he does not have the money. *(Wangu, 35, female, 1<sup>st</sup> interview HHD/diabetes/HIV)*

When my family heard my illness is lifelong they stopped helping. When I need money to buy my drugs they tell me they do not have the money to help. *(Njenga, 31, male, 1<sup>st</sup> interview, RHF/COPD)*

Tensions in relationships were not limited to existing relationships. New relations were also difficult to forge. Ndungu a middle-aged single man shared his experience of stigma in developing romantic relationships.

I am dating right now. When you tell someone about your condition they feel like they do not have a future with you. You are stigmatized. Some people are afraid because they would not want their children to inherit a disease. *[Ndungu, 50, male, 1<sup>st</sup> interview, DCM]*

## Financial issues

Most participants spoke of the challenges they faced in paying for their treatment particularly when costs accumulated as their illness progressed. Njenga, an informal businessman, described how the high cost of treatment was prohibitive.

One packet (Sildenafil) costs me Ksh 1,800 (£12).<sup>\*</sup> It has four tablets which is just enough for one day. It is expensive and you need a lot of money. (Njenga, 31, male, 1<sup>st</sup> interview, RHF/COPD)<sup>1</sup>

Patients felt unprepared for the financial commitment required to afford their care. Njambi described how her illness created a vicious cycle of poverty.

Being ill means poverty. Illness is poverty because you cannot make a living. I need to buy the medication but I also need money. If I am not able to work, how can I afford this? (Njambi, 60, female, 1<sup>st</sup> interview, HHD/myocardial infarction/asthma)

Over time, patients relied on financial help from family and friends. Some patients spoke of how fundraisers were organised to raise money for their treatment. However, these funds were often insufficient for the care they needed.

I need to buy some items for dialysis. My family had brought some money but it was not enough. I am waiting for them to bring more so we can buy what is needed. (Chera, 60, female, 1<sup>st</sup> interview, hypertensive heart disease' (HHD/Renal failure)

It costs Ksh 200,000 (£1000) to buy an oxygen concentrator to help me breathe better. We had a 'harambee' (fundraiser) but we did not raise the money needed. We did not even raise half. I feel my like my life is in danger ...it is hard for me to survive without the oxygen. (Njenga, 31, male, 2<sup>nd</sup> interview, RHF/COPD)

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<sup>\*</sup>75% of informal business owners earn Ksh 1,000-9,000 (£7-70) per month.

WORLD BANK. (2016) Kenya - Country Economic Memorandum [Online]. Washington, DC. Available: <http://documents.worldbank.org/curated/en/763771468197384854/pdf/103822-WP-Kenya-Country-Economic-Memorandum-PUBLIC.pdf> [Accessed 22 Feb 2017].

Although most patients described difficulties in affording their treatment, Shiru - a civil servant - explained how the national health insurance scheme was helpful in offsetting costs.

The national health insurance pays so I do not pay anything. I just go to the hospital and register. It is good. It helps a lot. I do not even pay for lab tests. Some blood tests are done at private hospitals and I do not pay.  
(Shiru, 57, female, 3<sup>rd</sup> interview, HHD/diabetes)

Patients with competing financial responsibilities explained how they had to decide between paying for their treatment and catering for other needs such as rent and school fees for their children.

Those drugs are expensive... I have a child and I need to pay his school fees. I used some of the money for school fees and the rest to buy the medicines. The money was only enough for a 2 week dose. (Ruguru, 50, female, 1st interview, HHD)

Others explained ways in which their progressive symptoms significantly increased their financial burdens. Ndungu shared how he could no longer walk to work and had to rely on public transportation to get around. This was an additional cost to him.

My symptoms have really affected my spending. I walk a lot on my job and now I have to use the bus (even for short distances) because of the breathlessness. Walking is no longer a form of exercise. It is a pain.  
(Ndungu, 50, male, 3<sup>rd</sup> interview, DCM)

## **Psychological issues**

Patients felt anxious after receiving their diagnosis. However, only some openly expressed their worry. Most patients responded stoically choosing to accept and endure their illness as fate or as the will of God. Underneath this stoic response, patients felt vulnerable. Njambi and Muthoni shared how they felt like they were at the mercy of God.



The best thing to do is to persevere and wait for the Lord. Only God has the last word. It is not worth thinking about it and if I do, I will only get worse. *(Njambi, 60, female, 1<sup>st</sup> interview, HHD/myocardial infarction/asthma)*

The disease is already in my body. I cannot do anything apart from accepting it. All I can do is continue taking my medication and maybe God will have mercy on me and heal me. *(Muthoni, 50, female, 1<sup>st</sup> interview, HHD, diabetes, angina)*

As the disease progressed patients who experienced worsening symptoms or readmissions expressed a heightened anxiety and fear. Shiru, a middle-aged woman who earlier shared her frustration and preferred a diagnosis of AIDS was worried her heart would 'stop'.

This illness of the heart, it is said that 'it' (the heart) can stop anytime. That is what I hear people say....like the local politician who recently died of a heart attack...my heart can stop. *(Shiru, 57, female, 1<sup>st</sup> interview, HHD/diabetes)*

Younger patients experienced significant anxiety and depression. One patient, Njenga, spoke about several attempts to end his life after recurrent admissions. Waithera also described how recurring symptoms triggered feelings of despair.

I think a lot about why this is happening and it makes me cry. I feel like jumping off the eighth floor of this hospital building. *(Njenga, 31, male, 1<sup>st</sup> interview, RHF/COPD)*

I feel sad especially when my legs and the rest of my body begins to 'swell'. At times I think I'm going to die. *(Waithera, 33, female, 2<sup>nd</sup> interview HHD)*

However, patients who were responsive to treatment and were experiencing periods of stability felt hopeful about their prognosis and even believed a cure was possible.

I feel okay. If I think too much about my heart condition then it will not be good for me. I'd rather encourage myself to believe that I will get better and heal from this illness. *(Jaba, 65, male, 3<sup>rd</sup> interview, DCM)*

## Spiritual Issues

Nearly all patients expressed a spiritual belief that God ordained all things.

This was not limited to illness but included life events in general.

All things are controlled by God. No human being can give or take from your life. Only God can do that. (*Samueli, 75, male, 3<sup>rd</sup> interview, RHF with COPD*)

I do not worry about my illness....God knows how long I will live. If this illness is his plan, I leave it to him. I leave everything to the Lord. (*Nanjala, 50, female, 2<sup>nd</sup> interview, HHD*)

Some patients often expressed confidence that God could alter the course of their illness despite the advice they received from their doctor. A few participants believed that if they endured their illness with fortitude, they would receive a reward or a blessing often in the form of recovery.

Even if the doctors say you will not get better God has his ways and a miracle can happen and you can get better. (*Njenga, 31, male, 3<sup>rd</sup> interview, RHF/COPD*)

These are trials. Before you receive a blessing, you must go through difficulties. I know there are blessings ahead. I will persevere and get through this. (*Waithera, 33, female 2<sup>nd</sup> interview, HTN*)

For most patients, belief in an all-knowing benevolent God was a source of comfort. However, when their condition deteriorated, they felt abandoned and questioned God. Shiru, who suffered with multimorbidity felt forsaken.

What have I done against you God? I have 'pressure', 'sugar (diabetes)', 'kidney' and heart problems. Why should I be the only one to have these problems? These illnesses are more than I can handle. (*Shiru, 57, female, 1<sup>st</sup> interview, HHD/diabetes*)

Many described the church as a place of solace. They spoke of the church as a place they could commune with God and share with others. However, two patients described their growing disappointment with the church. They felt

the church was not responsive to their needs and showed preference for people who gave more financially.

Nowadays the church is not helpful. If you do not offer tithe as expected no one cares. You see, I do not tithe all the time because I do not have money....I do not think they will help me. (*Wangu, 35, female, 2<sup>nd</sup> interview HHD/diabetes/HIV*)

When I told my pastor about my illness he discouraged me from going to church because the church is not for sick people. He did not seem concerned. Why should I be care about my church? (*Waithera, 33, female, 2<sup>nd</sup> interview, HHD*)

## **Uncertainty**

When asked about what they thought was likely to happen in the future, some patients were unsure what to expect. They spoke about how they did not anticipate a chronic illness but thought their condition was treatable.

I did not know what would happen. I did not think that this was a serious illness. I thought it was a small illness that would resolve with treatment. (*Nanjala, 50, female, 1<sup>st</sup> interview, HHD*)

Some who were already receiving treatment for other chronic illnesses also expressed that they did not expect to have a heart problem. Irungu, a middle-aged man with hypertension and diabetes shared how he was surprised by his diagnosis.

You know I did not think I would get ill. I had the 'sugar' problem first and the heart problem followed. I never thought I would have a heart problem. (*Irungu, 60 male, 1<sup>st</sup> interview, HHD, diabetes*)

When disclosing a diagnosis of heart failure to patients, health professionals would often use the terms 'your heart is getting bigger' or 'your heart is swelling' to describe an enlarged heart. This description would leave patients confused about their prognosis.

I am not sure whether my heart will remain the same size or get bigger. They said that my heart is large. Will it remain the same size? What will happen with treatment? (Ruguru, 50, female, 1st interview, HHD)

I do not know if I will get better... I wonder how my heart will become smaller and stop swelling. (Shiru, 57, female, 1<sup>st</sup> interview, HHD/diabetes)

Other patients shared how they thought their illness was meant for 'others' and not them. Some patients believed that their illness was meant for people of higher economic status who had different lifestyles and could afford expensive treatments.

We hear about rich people....people like politicians dying of heart attacks. Heart problems kill such people. That is why we think it is for the rich and not for people like us (Waithera, 33, female, 2<sup>nd</sup> interview, HHD)

At least a rich person can afford treatment and if things get worse they can even go to India for treatment. (Njenga, 31, male, 1<sup>st</sup> interview, RHF/COPD)

### **5.3 Dying with heart failure**

As patients approached the end of life, their physical well-being deteriorated. In addition, social, financial, psychological and spiritual problems became worse, and uncertainty pervaded. Most patients approached the end of life with little information on what to expect, and only one patient was aware of his prognosis. The following section presents salient themes as patients approached death.

#### **Physical issues**

As their illness deteriorated, patients were confined to their homes. Worsening symptoms limited daily activity and patients became dependent

on their family for daily care. Carers described how patients struggled in the last days of life.

She would say that she felt like her heart was being ripped from her chest. She could not get out of bed on her own. I had to carry her and place her outside the house while I worked, so I could keep an eye on her. (*Carer to Njambi 60, female, HHD/myocardial infarction/asthma*)

She was breathless....that was her main problem. She was not getting out of bed at all. She could not go to the toilet on her own. (*Carer to Ciru, 60, female, HHD*)

## Thoughts about death

Although most patients were not aware of their prognosis, they had thought about dying. After an acute episode, patients often felt anxious about the future. They were fearful that a similar episode would occur and wondered whether they would survive it.

Anything can happen at any time. It is the heart you know. What is life for? I can go anytime. (*Mbui, 50, male, 2<sup>nd</sup> interview, DCM*)

Sometimes I think about dying. I can die anytime and once I die that is the end of my life. (*Shiru, 57, female, 1<sup>st</sup> interview, HHD/diabetes*)

Some patients chose not to think about the possibility of death. They felt that such thoughts intensified their anxiety and would hasten their death.

If I think about my high blood pressure, 'sugar' and heart problem I will die. If I think about these things... my condition will get worse. When I worry about these things my heart starts to beat faster. (*Muthoni, 50, female, 1<sup>st</sup> interview, HHD, diabetes, angina*)

Others found it difficult to speak about dying as they believed that death was under God's control. Patients believed that God had authority over human life and people could die whether ill or not.

I would rather accept my life as is.....there are those who are not sick but die from other causes. Although, I am ill...I am still alive.....I accept my fate. (*Irungu, 60 male, 2<sup>nd</sup> interview, HHD/diabetes*)

There are people without heart problems yet they die and I am still alive.... I am only alive because of God's goodness. (*Waithera, 33, female, 2<sup>nd</sup> interview, HHD*)

For some patients death felt imminent especially when treatment failed to control symptoms. Patients felt distressed and frustrated which increased thoughts about dying.

Sometimes I wonder why I am not dying because I am not getting better with the treatment....was I meant to suffer like this forever? (*Njenga, 31, male, 1<sup>st</sup> interview, RHF/COPD*)

I feel like this illness limits me a lot. Even with the treatment... I think I am going to die. Death is all that is left for me. (*Shiru, 57, female, 1<sup>st</sup> interview, HHD/diabetes*)

Although most patients found it difficult to openly discuss dying, a few alluded to it by speaking about the preparations they had made. Specifically, one elderly patient explained how he had made arrangements for his children to inherit property.

I have made plans for every one of my children to inherit the family land but I will not give them the deeds yet. They will get that when I die. (*Samueli, 75, male, 3<sup>rd</sup> interview, RHF with COPD*)

## **Contacting family**

During their last days, two patients spoke about wanting to re-establish relationships. Contacting estranged family members was a way of making-up and saying good-bye.

When she was discharged from the hospital, she called her family to come see her. It is like she knew she was going to die. She called her brother and his family to come over. (*Carer to Njambi 60, female, HHD/myocardial infarction/asthma*)

Family is important. I have tried to work things out with my wife but she does not want to. What more can I do? (*Cege, 45, male, 1<sup>st</sup> interview right sided heart failure' (RHF) from COPD*)

Although patients were eager to re-establish relationships some preferred not to reveal their reasons for doing so as they were not ready to discuss dying.

There are some unresolved conflicts in the family. Maybe I can tell my brothers so we can resolve our conflicts. I will not tell them why I need to speak to them.... But I will know why...it is because of my illness but I am yet to tell them about it. (*Mbui, 50, male, 1<sup>st</sup> interview, DCM*)

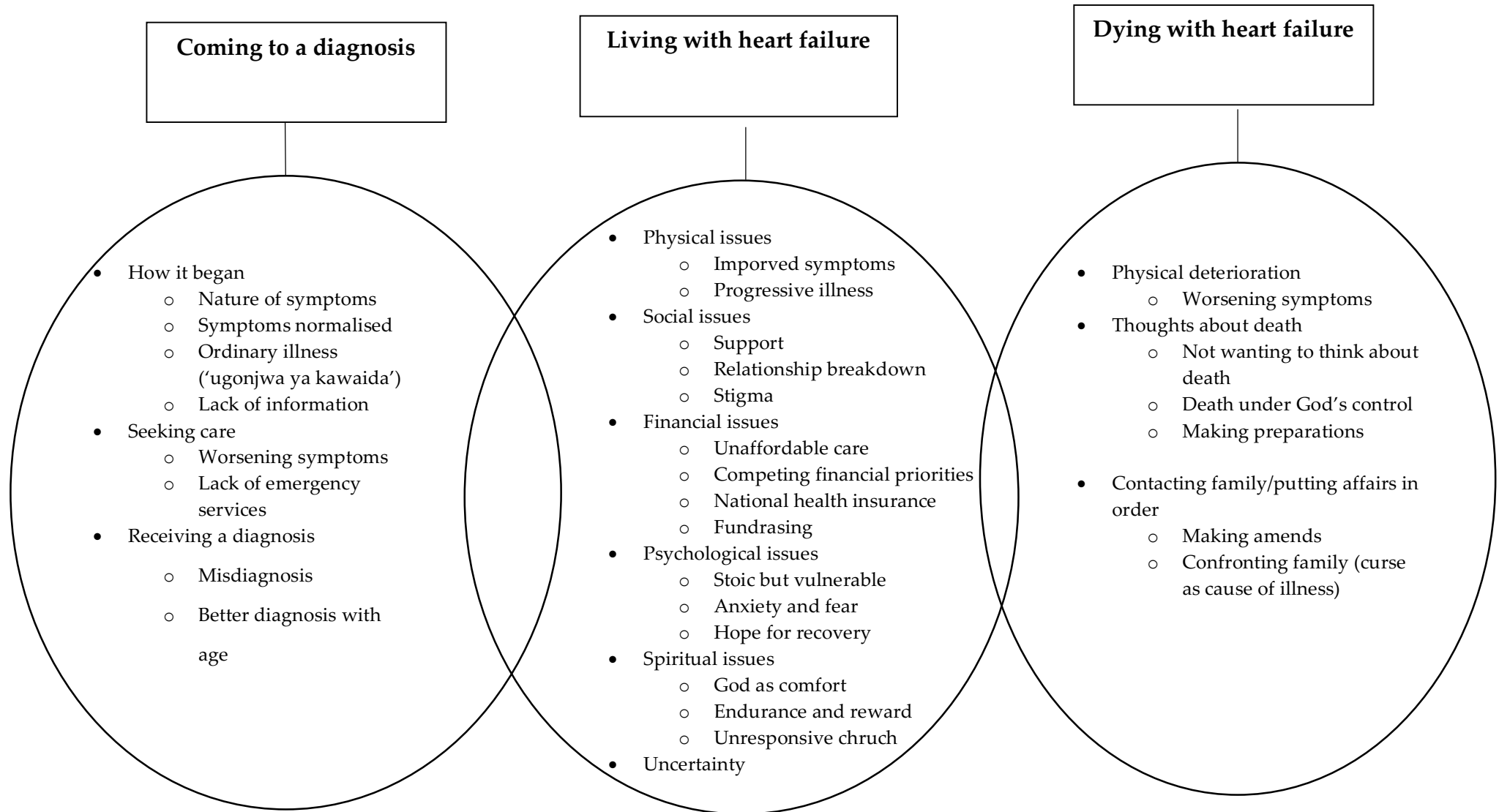
However, for one patient, re-establishing contact also meant confronting family members about past offences. Two days before her death, Wangu spoke about contacting her grandmother whom she suspected had cursed her and caused her illness.

I was not getting better with treatment... I got sick again. I thought it was because of problems I have with my grandmother. I asked her to come over and confirm if she is the one who cursed me with this illness. I confirmed it was not her. (*Wangu, 35, female, 1<sup>st</sup> interview HHD/diabetes/HIV*)

## **5.4 Discussion**

In the experience of living and dying with heart failure three significant phases were identified: (i) coming to a diagnosis (ii) living with heart failure and (iii) dying with heart failure. Figure 13 overleaf shows the main themes in each of these phases.

**Figure 13:** Themes of the experience of living and dying with heart failure in Kenya





## **Coming to a diagnosis**

This stage describes patients' experiences from the manifestation of physical symptoms to the confirmation of a heart failure diagnosis. Common symptoms included breathlessness, fatigue, oedema, cough and palpitations. Symptoms such as fatigue and cough were described as normal and linked to common acute conditions such as pneumonia or malaria.

Breathlessness was the most significant symptom. The manner in which patients experienced and interpreted breathlessness often influenced how they sought care. Acute onset breathlessness triggered feelings of fear and anxiety (Boyd et al., 2004 ; Horne and Payne, 2004) as patients sensed they were in immediate danger which prompted a decision to seek emergency care. Conversely, those with gradual onset breathlessness normalised this symptom, and in most cases, interpreted it as consequence of increased physical exertion. Michael Bury (1982) terms this 'proximal explanation' in reference to patients linking their symptoms to changes in their external environment. Only when breathlessness increased in severity and limited daily function did patients decide to seek care. Normalization may lead to delays in health care seeking as patients explain away their symptoms (Corner et al., 2005 ; Tod et al., 2008). Other heart failure symptoms such as fatigue and cough were interpreted as ordinary or normal and having no serious consequence.

When a decision to seek care is made, the ability to reach appropriate care depends on the capacity to organize efficient and effective pre-hospital emergency care. Some patients described the challenge of mobilizing transportation. Ambulances were rarely available, and patients relied on alternative modes of transportation manned by untrained personnel.

Kenya's emergency services remain underdeveloped, and the country lacks a

centralized system to coordinate the dispatch of emergency services. Patients are often transferred for emergency care using taxis, personal vehicles, or taxi motorbikes (Wachira and Martin, 2011). They are therefore left on their own to determine which health facility to attend, depending on their perception of the level of care they need (Broccoli et al., 2015). If patients perceive their symptom as a minor ailment, they often chose to attend a lower level facility (in the health system hierarchy) such as a clinic or private pharmacy that may not be well equipped to make a proper diagnosis. Inappropriate selection of where to seek care may further delay the making of an appropriate diagnosis.

When a patient arrives at the selected health facility, health system factors influence how a diagnosis is made. Diagnostic capacity, skilled human resources, availability of treatment protocols and access to essential medicines may affect the ability of a health facility to provide appropriate care (Calvello et al., 2015). In SSA, many health facilities lack the necessary capacity to effectively diagnose and treat chronic illnesses. Few health professionals have been trained to offer specialist chronic disease care, and knowledge on chronic disease management remains low (de-Graft Aikins et al., 2010b). For example, in Kenya, a survey of 143 health facilities found only 36% had a staffed and working electrocardiogram machine (Durakovic et al., 2015). Lack of appropriate diagnostic equipment may lead to mis or under-diagnosis of heart failure (Bloomfield et al., 2013).

In this study, nearly half of patients were initially diagnosed with a common acute condition such as malaria or pneumonia. Interestingly, younger patients were more likely to receive this diagnosis. As noted in Chapter 2, heart failure in SSA occurs in a younger age group compared to high-income countries. Associating chronic disease with ageing may mean that health

professionals may not initially identify heart failure as a possible diagnosis in younger people which may delay a definite diagnosis (Abegunde et al., 2007).

## **Living with heart failure**

In this phase, patients hovered between a state of hope and despair. Improved physical symptoms often triggered feelings of hope for recovery. In particular, better breathing was interpreted as a general improvement in well-being and patients looked forward to returning to normal life. However, the onset of an acute episode dissipated this hope. Anxiety dominated as patients worried about their future. The accumulating costs of care aggravated negative emotions as patients struggled to meet financial demands. Many coped by relying on their spiritual beliefs and the support they received from social networks.

During acute episodes, patients experienced a broader loss of self beyond their physical suffering. Charmaz (1983) identifies four themes that characterise the loss of self in patients with chronic illness: a restricted life, social isolation, being discredited by others and becoming a burden. These four themes are represented in this study. For instance, worsening physical symptoms meant that patients were unable to fully participate in activities of daily life. Patients expected to keep up with social roles such as working and engaging with social networks at home and in their community. For most, a restricted life was a difficult reality to come to terms with as patients wanted to maintain their independence to work and support their families. Loss of independence increased negative emotions particularly in younger patients who struggled to keep up with societal expectations to provide for their

families (Moser et al., 2013). Many patients relied on income from their farms or self-run businesses to make ends meet. Social services are limited in Kenya (Dixon, 2016:116) and most patients would depend on family members to help pay for care. This financial burden increased the risk of families falling further into poverty (WHO, 2005) which heightened tensions in relationships. Patients experienced further social isolation as they felt abandoned by family and friends.

Beyond multidimensional loss, patients experienced pervasive uncertainty. In the theory of uncertainty in chronic illness Mishel (1988b) defines uncertainty as 'the inability to make sense of illness related events'. Three themes constitute the theory of uncertainty (i) antecedents or stimuli of uncertainty (ii) appraisal of uncertainty (iii) coping with uncertainty. Each of these will be reviewed with reference to this study's findings.

### **Antecedents of uncertainty**

Uncertainty occurs when a person is unable to effectively interpret their illness, treatment or hospitalization. Antecedents or stimuli for the onset of uncertainty include illness symptom pattern, event familiarity, and event congruency. Symptom pattern refers to the degree in which symptoms are consistent to form a recognisable pattern while event familiarity is the extent to which a set of circumstances are repetitive or habitual (Mishel, 1988a) Event congruency refers to the uniformity between what a person expects to happen and how an illness is actually experienced. Interpretation of stimuli depends on *cognitive functioning, having a sense of competence* to interpret stimuli (Wright et al., 2009) and *structural factors* such as social support, education level and credible authority from health workers. Structural

factors help patients make sense of illness events and thereby reduce uncertainty (Mishel, 1990).

Patients with gradual onset breathlessness and fatigue expressed a sense of familiarity with their symptoms. They described previous experiences with treatable common illnesses, which presented with symptoms similar to those of heart failure and formed a recognisable pattern. In turn, this may have led patients to believe that their illness was 'ordinary' and curable. At this point, patients were able to discern their illness event which limited their uncertainty.

However, with recurrent acute episodes patients struggled to make sense of their illness. Symptoms became increasingly unfamiliar, and there was little uniformity between their past illness experiences and what they expected (recovery). With each acute episode, patients felt a greater loss of control over the future. Poor social support and lack of information and effective communication from health professionals increased patients' anxiety as they struggled to make sense of their experience. The effect of poor communication and lack of information will be discussed in subsequent chapters reviewing patients' experiences with and preferences for care.

### **Appraisal of uncertainty**

Once uncertainty occurs, it can be appraised as danger or as an opportunity. If uncertainty is evaluated as danger, coping strategies are activated to reduce uncertainty. Uncertainty is appraised as an opportunity when evaluated against a more likely negative outcome such as death. As a result, coping strategies such as avoidance or denial are applied to help disengage with but support a state of uncertainty (Mishel, 1990 ; Mishel, 1988b).

In this study, patients struggled to make sense of progressive physical symptoms. This heightened feelings of fear and anxiety with some patients describing a sense of their life being in danger. This sense was more marked in younger patients who had higher expectations of recovery than those who were older. For older patients, a decline in physical well-being was more acceptable and interpreted in the wider context of aging.

### **Coping with uncertainty**

How a person copes is influenced by social, psychological, spiritual and material resources (Folkman, 2013). Most patients who appraised uncertainty as danger coped by relying on social support, spiritual resources, and information seeking to decrease the effect of negative emotions. Spirituality and social support have been found to foster hope (Herth, 1990) and reduce negative emotions. Support from social networks (family, friends, workmates, and church members) promoted feelings of interconnectedness as patients felt less alone. The belief that God was in control of their illness and life, in general, helped patients make sense of their experience. Spirituality supports patients to adjust positively to illness by helping them maintain hope and optimism and find meaning in challenging life circumstances (Westlake and Dracup, 2001). Those who may have appraised uncertainty as opportunity coped by using strategies such as denial and avoidance. However, this interpretation is made cautiously given patients low level of understanding about heart failure.

## **Dying with heart failure**

In the last weeks of life, patients' physical well-being declined and the uncertainty described above continued to dominate. Patients remained unaware of their prognosis and worried that they would not survive another acute episode.

Although patients acknowledged the possibility of death, few openly spoke about dying. In most African cultures, death is interpreted through a religious lens. Death is thought to be a consequence of spiritual causes such as the will of God rather than medical reasons. In most communities, it is considered taboo to think or speak about death. Written preparations towards dying (such as wills) are rarely made although elderly patients may give verbal instructions of their wishes before death (Ekore and Lanre-Abass, 2016). Life is viewed as a kinship between the community and God (Omonzejele, 2008) and attempts are made to ensure harmony before one dies. For example, some patients spoke of wanting to know whether a curse or witchcraft had caused their illness. They did this by seeking out family members with whom they had complicated relationships, which was as a way of making peace with loved ones and with the spiritual world.

## Chapter 6 : Experience of care for patients with heart failure

Using three key phases of the illness journey identified in Chapter 5 this chapter recounts experiences with care from the perspectives of patients and their bereaved carers.

### 6.1 Care around diagnosis

#### Prelude

Prior to diagnosis, sixteen patients reported they had received treatment for conditions other than heart failure. These included hypertension (n=4), diabetes (n=4), asthma (n=4), tuberculosis (n=3), pneumonia (n=3), COPD (n=3) and undiagnosed illnesses (n=3). In some cases, patients had multiple diagnoses.

The type of health facility patients decided first to attend varied. Most attended government run facilities (n=10). Others sought care at private clinics (n=5) and mission hospitals (n=3). However, not all patients attended a health facility. One patient, Nanjala, choose to self-medicate with traditional medicine.

I was told about some 'medicine' sold by the 'maasai' community. It helps you pass water. I took it, the swelling subsided and I felt better... it was a reddish liquid....they got some leaves from the forest... they told me to boil a glass of the liquid in the morning and one in the evening.  
(Nanjala, 50, female, 1<sup>st</sup> interview, HHD)



## Where to go

For most patients, distance influenced the choice of which health facility to attend. Patients were often caught unaware by acute symptoms and the closest health facility was preferred for immediate relief of symptoms. Those who went to lower level facilities (such as dispensaries, health centres and clinics) often faced challenges as these facilities were ill equipped to make a diagnosis.

I was breathless. I went a local council clinic but they were not able to treat me.... they did not help me much. They told me they could not help me because they did not have the 'machines' to make a diagnosis. They referred me to a 'bigger' hospital. (*Jamo, 36, male, 1<sup>st</sup> interview COPD*)

I was fatigued. I went to a nearby health centre. They examined me and referred me to the government district hospital. I went to the health centre because it is near but when you have a serious illness they send you to the district hospital (*Irungu, 60 male, 1<sup>st</sup> interview, HHD/diabetes*).

When treatment failed to resolve symptoms, patients were often referred to better-equipped facilities to confirm a diagnosis. Mbui, who was initially misdiagnosed with asthma at a local dispensary, spoke about how his doctor referred him to the district hospital after he failed to respond to treatment.

I could not breathe at all....so I went to the local dispensary. They gave me some medicine and told me I am asthmatic. The doctor treated me for asthma for almost a month but there was no change. He suspected something else was wrong... something to do with the heart. He said: 'I have been giving you these medicines and they are not helping you, there must be another problem'. He decided to refer me to the district hospital for further care. (*Mbui, 50, male, 1<sup>st</sup> interview, DCM*)

For patients who sought treatment at higher-level facilities such as district or mission hospitals, diagnosis of heart failure was more straightforward. These facilities were better equipped to confirm a diagnosis.

It started with breathlessness. I went to the district hospital and I was told that I had a 'heart problem. Then I developed kidney problems and I

was referred to the national hospital for advanced care. (*Chera, 60, female, 1<sup>st</sup> interview, HHD/Renal failure*)

When I fell ill I went to the district hospital. Then they sent me to the x-ray department. That is when they told me I have a heart problem. (*Ruguru, 50, female, 1<sup>st</sup> interview, HHD*)

## **Receiving the diagnosis**

Patients described varied experiences of how they received their diagnosis.

At the early stages of their illness, most patients were unaware of their diagnosis. They waited for health professionals to discuss their condition.

Interviewer: Have the doctors talked to you about your problem?

Wangu: They have not really told me what is wrong... they have not told me much about my heart. (*Female, 35, 1<sup>st</sup> interview HHD/diabetes/HIV*)

It started with my legs swelling....then they did some tests and they told me that my heart was swelling. But I still do not know what was going on....they have not told me. (*Nanjala, 50, female, 1<sup>st</sup> interview, HHD*)

Most patients learned of their diagnosis from discussions with health professionals while receiving treatment on the ward. They were told they had a 'heart problem' and were advised to adhere to their treatment.

However, the chronic nature of their illness was rarely discussed.

(*Field notes – 31<sup>st</sup> January 2015*).

Not all patients learned about their diagnosis from one-on-one discussions with health professionals. Irungu explained how he became aware of his diagnosis when health professionals and medical students discussed his condition during a ward round.

Interviewer: What type of care are you receiving?

Irungu: I was told that they are treating a heart problem

Interviewer: When did the doctor speak to you about this?

Irungu: The doctor did not speak to me about it...but I heard them talk about it on the ward

*(Irungu, 60 male, 1<sup>st</sup> interview, HHD, diabetes)*

Others spoke about how they learned of their illness by talking with other patients on the ward.

I did not know that there is an illness that affects the heart. The doctors had asked me to get an x-ray done but I refused to do it. It is only when other patients on the ward told me that they have a similar illness that I believed that there is an illness that can affect the heart. *(Nyambu, 31, female, 1<sup>st</sup> interview, DCM)*

I heard about this illness the other day when I spoke to other patients. When you speak to them they tell you they suffer from breathlessness too. *(Jamo, 36, male, 1<sup>st</sup> interview, RHF/COPD)*

Patients responded differently to their diagnosis. Some patients felt unsettled, as they had not heard of a condition affecting the heart.

I did not believe what they doctor was telling me. I was shocked by what he told me. I asked him not to tell me anymore. After he spoke to me my condition got worse. I had never heard of a heart condition before. *(Ruguru, 50, female, 1<sup>st</sup> interview, HHD)*

Patients were concerned that their heart had a problem. They felt their heart was an important organ and having a 'heart problem' meant their condition was serious.

I was shocked when the doctor told me about my heart problem. I was afraid....you know the heart is everything. *(Bui, 19, female, 2<sup>nd</sup> interview, edidiabetesextra pulmonary tuberculosis)*

Others did not know what it meant to have a heart problem, but chose to accept their diagnosis. They found comfort in knowing they were not alone and there were other people facing similar illness.

When I went to the clinic, I saw other people who were very ill...more than I am. It is better for me to accept my illness. Why should I complain? *(Irungu, 60, male, 2<sup>nd</sup> interview, HHD/diabetes)*

By the end of the study, all patients knew they had a 'heart problem', but most were unaware what their diagnosis meant.

## **6.2 Experience of care when living with heart failure**

### **Discontinuity of care**

Patients shared their experiences with care over time. Most patients (n=13) described how they went to different facilities for treatment. Two of these were referred by health professionals: one required advanced treatment not available at the district hospital, and the other was advised to seek care at a lower level facility closer to home as she was on treatment for extrapulmonary tuberculosis.

However, the other eleven patients self-referred to other facilities. Some patients sought alternative health providers when they felt unsatisfied with the quality and cost of the care they were receiving.

The doctors at the district hospital did not refer me. I told them to discharge me so I could go get the x-rays done at the national hospital. I knew the national hospital would be better that is why I had to get out. If I was not discharged I would not have known my diagnosis. (*Mbui, 50, male, 1<sup>st</sup> interview, DCM*)

I do not want to go back to the district hospital. I did not like it and I did not get along with one of the nurses. I prefer the private clinic nearby. Their drugs are helpful and sometimes they give me drugs on credit. (*Waithera, 33, female, 2<sup>nd</sup> interview, HHD*)

Although self-referral allowed patients to seek care at a health provider of their choice, Shiru described her frustration at having her condition re-diagnosed at each new facility she attended. Discontinuous medical records were a significant problem.

First I went to a mission hospital but the drugs were not helping. I decided to go to another mission clinic. They took an x-ray and prescribed treatment. They also told me to get an 'echo' for the heart. They referred me to the district hospital. Here the doctors started all over again with the tests. Then they referred me to the national hospital for other tests. *(Shiru, 57, female, 1<sup>st</sup> interview, HHD/diabetes)*

Over time, financial costs also influenced where patients would seek care. Often, facilities closest to home were preferred as patients incurred fewer costs. Jaba, a middle-aged man, explained how additional indirect costs influenced where he sought care.

I buy medicine from a chemist that is nearby. I found the prices at the chemist and at the district hospital similar. I spend Ksh 1500 (£10) per month...if I go to the district hospital, I will need to pay bus fare but for the nearby chemist I do not use any extra money. *(Jaba, 65, male, 1<sup>st</sup> interview, DCM)*

However, not all patients changed health providers. One patient explained how he preferred to receive care from one facility as this ensured continuity in care.

I have gone to the national hospital many times. I prefer to go there. They are the ones who diagnosed my condition. All my health records are there. *(Njenga, 31, male, 2<sup>nd</sup> interview, RHF/COPD)*

## **Lack of communication with health professionals**

Most patients spoke about the challenges they faced when speaking to health professionals about their illness. Patients felt anxious, not knowing where to begin.

Interviewer: Do you get a chance to ask questions?

Shiru: No. You know it is hard.... where do you start. You know doctors are to be feared

Interviewer: You are afraid to speak to them?

Shiru: I do not know them well. It is difficult to speak to them.

*(Female, 57, 1<sup>st</sup> interview, HHD/diabetes)*

Some patients felt that asking about their illness meant that they had little

trust in health professionals. They worried that it would jeopardise their treatment.

You know most people fear doctors. There is this fear that has been placed in people.... you cannot ask a question. If you ask a doctor a question it is like you are trying to disapprove his or her assessment. That stops you from asking questions. (*Jaba, 65, male, 1<sup>st</sup> interview, DCM*)

Some patients believed doctors possessed God-given knowledge about their heart problem. They felt it was important to co-operate with doctors so that they would receive the right treatment and experience a full recovery. At times these beliefs hindered communication as patients felt they were going against God if they enquired about their illness.

You know the doctor is guided by God. Human beings cannot treat themselves. God guides doctors to make the right diagnosis. It is not only the doctor's education but God's guidance. You should accept the doctor's advice because God is with them. I do not know much about this illness but if I follow the doctor's instructions, I will heal from this illness. (*Samueli, 75, male, 2<sup>nd</sup> interview, RHF with COPD*)

I must speak to the doctors because I have come to them for help. You must be humble and tell them how you feel...so that God intervenes for you. (*Ruguru, 50, female, 1<sup>st</sup> interview, HHD*)

However, not all patients expressed similar beliefs. Some patients shared that they were aware that health professionals were knowledgeable in regards to their illness but this did not equate them to God.

I cannot say a human being is God. They (doctors) do God's work but they are not God. If they were God I would be healed. (*Shiru, 57, female, 3<sup>rd</sup> interview, HHD/diabetes*)

The doctor treats but God heals. The doctor is a human being like me. It is just that they have been trained to treat people. However, I must respect the doctors because I am in their care. (*Waithera, 33, female, 2<sup>nd</sup> interview, HHD*)

## 6.3 Care around dying with heart failure

### Increasing contact with health care

During their last days, some patients frequently sought and expressed a preference for hospital care. The time between hospital visits shortened as patients felt overwhelmed by their deteriorating health. Sometimes patients would self-refer to other health facilities in search for the treatment that would cure their illness, which intensified the discontinuity of care.

When my condition got worse I changed hospitals. I stopped going to the district hospital and went to the mission hospital. From the mission hospital I went to the national hospital and they prescribed treatment...I have noted some changes in my condition. (Wangu, 35, female, 3rd interview HHD/diabetes/HIV)

Most patients preferred hospital care as they believed they would get relief from their acute symptoms. Pain was a major concern.

She knew she would get pain treatment at the hospital. She was in pain while at home. She preferred the hospital because she would not be in pain. (Carer to Njambi, 60, female, HHD/myocardial infarction/asthma)

In the event that treatment at a local hospital could not offer a cure, patients shared how they would raise funds to seek advanced treatment abroad.

If possible, I would like to have a lung transplant.... I would like to go to India for the transplant but I will have to raise the money. (Njenga, 31, male, 1<sup>st</sup> interview, RHF/COPD)

### Lack of communication with health professionals

Some patients described the challenges they faced with doctors in speaking about death. Patients thought that death was a forbidden topic that doctors were not permitted to discuss.

I am not get better. It is like the doctor did not want to tell me because I was on treatment for one and half years before they told me. You know

they cannot tell you directly that you will not get better. You know doctors are not allowed to do so. They wait for you to die. (Njenga, 31, male, 3rd interview, RHF/COPD)

Patients were also afraid to ask about their prognosis as they felt health professionals would rebuke them. During his final days, one patient narrated his difficulties in initiating conversations with his doctors.

I have never thought to ask them questions. It is hard to approach them....they might say that this illness is their responsibility and that I should not ask any questions. (Cege, 45, male, 2<sup>nd</sup> interview right sided heart failure' (RHF) from COPD)

Over time patients expressed the need to understand more about their illness. This need for information was heightened towards the last days, as patients and their families were trying to come to terms with an illness not responding to treatment. In the absence of information from health professionals, patients and carers relied on their own understandings. At times, participants believed that failure to adhere to cultural norms resulted in illness and death. For instance, one carer explained how her mother's failure to follow cultural practices regarding payment of dowry had caused her illness.

Mum's granddaughter was getting married. There was a dowry ceremony at home but mum kept the money for herself. She was not meant to and that's when her problems (illness) started. When she died, we thought that is what had caused her illness. (*Carer of Ciru, 60, female, HHD*)

Similar thoughts were expressed by another female patient who described how her family felt that her persisting illness was caused by failure to share a dowry payment. She felt she needed to appease her family so that they would refrain from blaming her for her illness.

I was given a goat for my daughter's dowry, but I sold it. My younger brother complained about this and said that is why I was ill. I had to



buy the family another goat so that they would leave me alone. (*Shiru, 57, female, 2<sup>nd</sup> interview, HHD/diabetes*)

Other participants expressed a belief that their illness was caused by a curse especially from family members with whom they had difficult relationships.

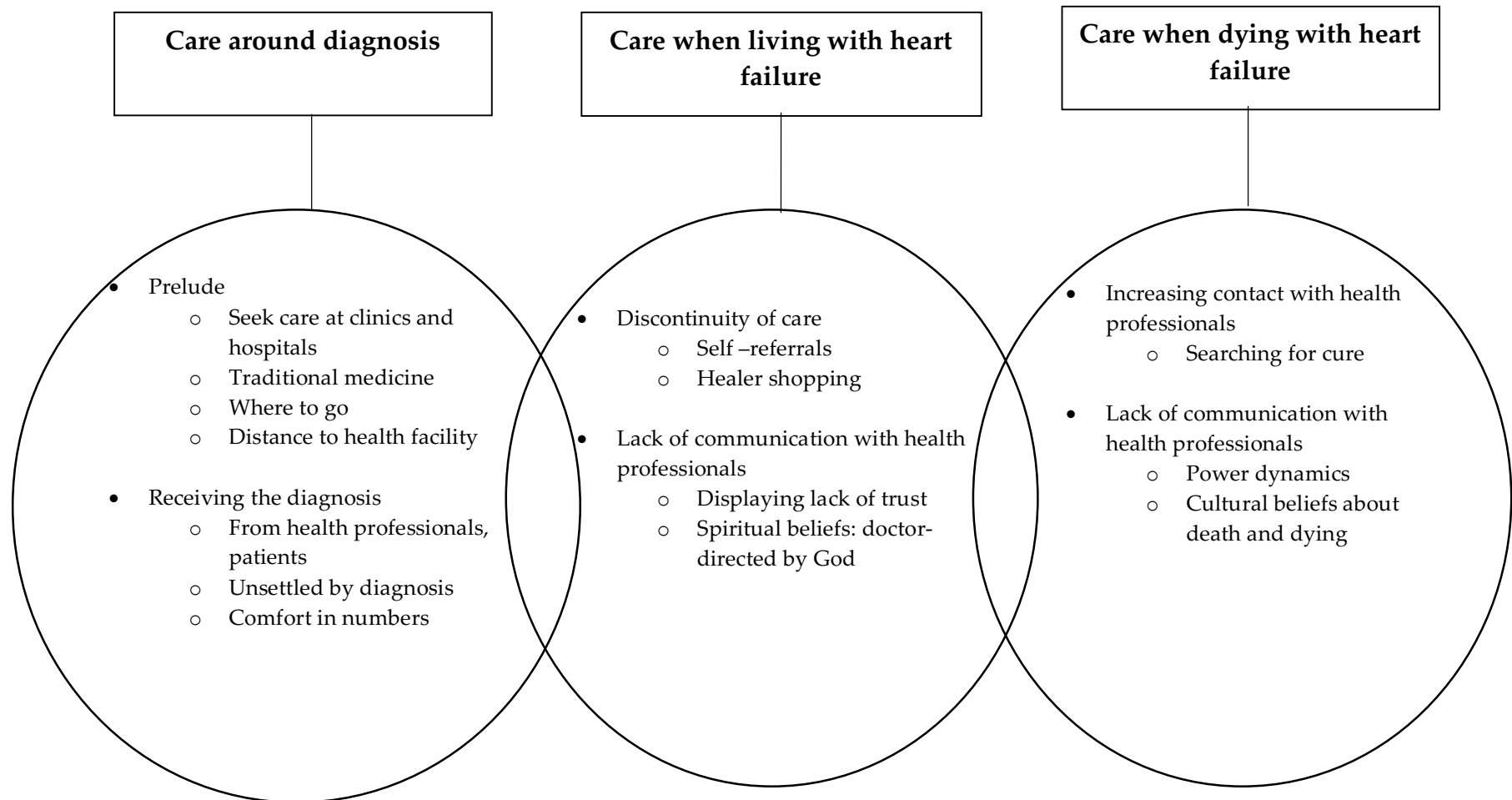
I feel like this illness is a curse....I was cursed so that my life would not continue....I think my stepmother cursed me. (*Njenga, 31, male, 3<sup>rd</sup> interview, RHF/COPD*)

## **6.4 Discussion**

In exploring patients' experience with the care, three main phases were identified (i) the care around diagnosis (ii) experience with care when living with heart failure (iii) experience with care when dying with heart failure.

Figure 14 on the next page shows the main themes in each phase.

**Figure 14:** Themes of the experience of care patients living and dying with heart failure in Kenya



## Care around diagnosis

Kenya's health system is a hierarchical pyramid with village dispensaries at the lowest level and national referral hospitals at the top. District hospitals sit in the middle of the health system and are the first referral hospital in the public health care system. Dispensaries and health centres are closest to communities and mainly offer maternal and child health care, basic treatment for common infectious diseases, and preventive care (immunisations) (Muga et al., 2005). They are managed by a trained nurse or a clinical officer<sup>2</sup>.

The onset of acute symptoms led patients to seek care at the closest health facility. In most cases, this was a lower level hospital, dispensary/health centre, private clinic or pharmacy. When symptoms failed to resolve patients often self-referred to better-equipped health facilities. Facilities such as district hospitals, which were higher up in the health system hierarchy, had more diagnostic equipment and better-trained personnel to make a diagnosis of heart failure. Local dispensaries and health centres may lack necessary equipment and skilled human resource for chronic disease care.

Patients who at first instance went to the district hospital had a heart failure diagnosis confirmed earlier. The district hospital had a radiology department where chest x-rays were performed. If additional tests (echocardiography, electrocardiography) were needed, the hospital was able to arrange this although patients had to pay out of pocket. The district hospital also had better-trained staff including consultant physician, medical officers (doctors who have completed their general training), trainee doctors and nurses.

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<sup>2</sup> Medical health professionals trained to offer care alongside physicians or independently

However, not all participants sought care at a formal health facility. One patient chose to use traditional medicine (herbs) prior to seeking care at a hospital. These findings bring to light the pluralistic nature of Kenya's health care system in which public and private health facilities co-exist with traditional approaches. Factors that influence a patient's choice of where to seek care are multiple and complex. Studies from Kenya exploring how patients' determine where to seek care identify the distance from home, the cost of treatment, patients' knowledge on the severity of their illness, and a health care provider's reputation as significant factors (Nyamongo, 2002 ; Bigogo et al., 2010). Patients often take a pragmatic approach and choose where to seek care place based on distance and the cost of treatment (Van Damme et al., 2010). In this study, distance was an important factor particularly during acute episodes when patients required urgent care.

## **Experiencing care while living with heart failure**

Two themes emerged from this phase: discontinuity of care and lack of communication with health professionals. Problems with communication were significant and ran across the patient journey from diagnosis to death. Challenges with communication will be discussed as a crosscutting theme in a subsequent section.

## **Discontinuity of care**

After discharge, thirteen patients did not return to the recruiting hospital for follow-up care. Most were unsatisfied with the quality and cost of care and self-referred to other facilities. Seeking care at an alternative facility meant

that patients had to be re-diagnosed since medical records were not available to multiple health providers. Access to electronic medical records is limited as most facilities rely on paper-based systems.

Cost and quality of care, convenient location of services, availability of pluralistic health services, and cultural beliefs on causation of chronic illness have been identified as factors that influence a patient's decision to change health care providers. From the anthropology literature, "healer shopping" is a term used, mostly in developing countries, to describe this phenomenon. It is defined as the 'use of a second healer without a referral from the first for a single episode of illness' (Kroege, 1983:147). In Africa, "healer shopping" is directed by (i) a patient's need for cure (ii) the belief that chronic illnesses have a spiritual origin and (iii) trust in traditional medicine (de-Graft Aikins, 2005). It is regarded as a patient-directed strategy of dealing with care perceived to be of low quality (Benson et al., 2015:122).

Most patients hoped to recover, and the need to regain a sense of control and return to normal life was important particularly for those of working age. Patients' steady belief that God could cure their illness may have driven them to seek multiple health providers in search for a cure. Although hope for cure was pervasive, not all patients could meet the costs of seeking alternative care. For some the accumulative cost of care including indirect costs, such as transportation, were prohibitive.

### **Experience of care when dying with heart failure**

During the last days of life, patients accessed care more frequently. As physical symptoms deteriorated, "healer shopping" continued into the last days, and many remained unaware of their prognosis. Patients expressed a

preference for hospital care with a few wanting to seek curative care abroad (in India)<sup>3</sup>. Symptom management particularly pain control is a significant concern for people at the end of life in Kenya (Downing et al., 2012) and can influence a patient's preference for hospital care at this time. Culture and spirituality also shape patients' preferences for further medical treatment. For example in African communities, death is considered an 'enemy of life'. This belief may lead people to want to preserve life even when medical treatment might be futile (Ekore and Lanre-Abass, 2016).

### **Lack of communication with health professionals**

While most patients were told they had a heart problem few understood what this meant. At diagnosis, patients responded with shock at the news that they had a heart problem. Although many were unfamiliar with a diagnosis of heart failure, they viewed their heart as a vital body organ and perceived their illness to be serious. Patients wanted more information about their condition and what they should expect in the future.

Most patients expressed a need for more information and better communication with their health care provider. This need was evident at the time of diagnosis through to their last days of life. Although patients were in need of information and wanted to initiate conversations with health professionals, they felt doing so indicated they lacked confidence in those providing their care. When information was not forthcoming, patients relied

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<sup>3</sup> India is an increasingly popular destination for Africans seeking specialized treatment. It is favoured for its access to cost effective care and skilled health professionals.

Source: United Nations African Renewal (2016) India's medical tourism gets Africans' attention. Available at: <http://www.un.org/africarenewal/magazine/december-2016-march-2017/india%E2%80%99s-medical-tourism-gets-africans%E2%80%99-attention>.

on cultural and spiritual beliefs to make sense of their illness especially when their physical symptoms were not improving.

For many patients, initiating communication with health professionals was challenging. Patients spoke about barriers they faced in starting conversations. Many feared that asking questions about their illness meant they disapproved the treatment they were receiving. Some patients believed that God could cure through health professionals and it would be inappropriate to ask questions, as this would equate to questioning God, which would jeopardise the possibility of a cure. This meant that, although patients wanted to know more about their illness, they suffered in silence with an illness they knew little about. In the last days, the need for information intensified, as patients' experienced greater uncertainty, especially with frequent repeat admissions. Poor communication with health professionals led patients to seek information from other sources. Cultural understandings of disease, such as curses or witchcraft, were used to make sense of their illness. Reliance on cultural beliefs was common especially when medical treatment failed to control symptoms (de-Graft Aikins, 2005).

Power dynamics between patients and physicians is well known in medical culture. Differences in level of knowledge, social, and financial status between patients and doctors are sources of power expressed during a medical encounter (Goodyear-Smith and Buetow, 2001). For example, more than half of patients in this study had a primary or lower level of education and had minimal understanding of their illness with little access to credible sources of health information. These factors, in addition to the societal and financial status granted to doctors and other health professionals, may have contributed to a power dynamic in which patients felt they lacked confidence to initiate conversations. In this setting, patient autonomy was also minimal

and limited to accepting a health professional's recommendation (Emanuel and Emanuel, 1992).



## Chapter 7 : Patients' views on how their care can be improved

This chapter presents patients' views for better services. Six themes were identified (i) preference for a definitive diagnosis (ii) affordable care (iii) more information about the illness (iv) better communication with health professionals (v) better hospital environment and (vi) planning for the future. These themes cut across patients' illness journey.

### 7.1 Preference for a definitive diagnosis

Most patients anticipated recovery. However, when physical symptoms failed to resolve some patients felt that they had not received a correct diagnosis. They felt further medical assessments would lead to a conclusive diagnosis.

I would like the doctor to examine me properly to know the extent of my heart condition so that they can get the right treatment for me. (*Waithera, 33, female, 2<sup>nd</sup> interview, HHD*)

As patients continued with their treatment, some were frustrated by persistent symptoms and opted to seek care at an alternative facility in the hope of a cure.

I would like to change hospitals...maybe I will go to the national hospital. I know I will get a lung specialist there. Right now I am going to the mission hospital and I use a lot of money there and I am not getting better. (*Shiru, 57, female, 3<sup>rd</sup> interview, HHD/diabetes*)

However, patients whose illness was relatively stable throughout the study period felt satisfied with their diagnosis and were happy to continue receiving care at a single facility.

It is not good to move from one hospital to another. Some hospitals are looking for financial gain. They will tell you 'take this and take that'. It is

better to follow one way. (Samueli, 75, male, 3<sup>rd</sup> interview, RHF with COPD)

## 7.2 Affordable care

Patients shared the challenges they faced in meeting the expenses of their care. These expenses included direct costs such as hospital visits, diagnostic testing and treatment, and indirect costs from days off work, transportation to hospital and paying for household assistance. At times patients felt these costs were out of their reach, which negatively affected their continuity of care.

Before I could walk to the market but now I need to pay for a taxi or a motorbike. These are additional costs. Before I could manage on my own but now I need help. I cannot do the laundry anymore. I need to pay someone to do it. Each load is Ksh 400 (£2.70). I also need to buy formula milk because I cannot breastfeed my baby. That costs Ksh 1,200 (£8) per week. These costs can go up to Ksh 10,000 (£68) per month. Sometimes I do not have money for this. (Nyambu, 31, female, 1<sup>st</sup> interview, DCM)

I was told I needed to go to the clinic but I could not afford the consultation fee of Ksh 200 (£1.50). I also need money to travel to the hospital. I was not working so I did not have money to go to the clinic. Instead I stayed at home and bought the drugs I needed from the chemist. (Cege, 45, male, 1<sup>st</sup> interview right sided heart failure' (RHF) from COPD)

In view of these challenges, patients expressed the need for assistance in affording their care. Some patients, especially those who received little financial support from their family felt that this responsibility should fall on the government.

I need Ksh 200,000 (£1000) for my treatment. We had a harambee' (fundraiser) and were not able to raise the money needed. We did not even raise half. I hope the government can help because I do not have parents or anyone who can help me. I feel my life is in danger and it is

hard for me to survive without the treatment I need. (Njenga, 31, male, 1<sup>st</sup> interview, RHF/COPD)

When admitted, patients described how the drugs they needed were out of stock. This meant that they had to purchase their medicines from private pharmacies which were expensive and added to the cost of care. Patients believed that drugs supplied by the public hospital would be cheaper than those purchased at private health facilities.

It would be helpful if the hospital has its own medication. Right now there are no drugs in the hospital. We have to buy drugs from private chemists. It is expensive. For example one dose for treating pressure cost Ksh 2,600 (£17) (Nyambu, 31, female, 1<sup>st</sup> interview, DCM)

Since supply of medicines at the public hospital was unreliable, patients had to wait for a relative to visit to buy drugs for them. This was especially difficult for those with little financial or social support as it delayed their treatment.

The doctor told me to buy some drugs but nobody from home comes to visit so that they can buy the drugs for me. The prescription is still by my bed side. Where will I get the drugs from? (Cege, 45, male, 1<sup>st</sup> interview right sided heart failure' (RHF) from COPD)

### **7.3 More information about the illness**

Patients expressed a need for information regarding their illness.

Particularly, patients wanted to understand what had caused their illness.

If someone explained to me how this illness started and how it can leave my body. That would be helpful. (Nanjala, 50, female, 1<sup>st</sup> interview, HHD)

I would like to know what causes this illness and how you can treat it or what you should do when you have the signs. (Wangu, 35, female, 2<sup>nd</sup> interview HHD, diabetes, HIV)

Most patients wanted to know how to prevent their illness from occurring again (primary prevention from their point of view). Once treated for an

acute episode, some patients assumed that they were getting better and wanted to avoid experiencing a similar episode in the future.

It would be good if the doctor explains to me what I can do to prevent this heart problem...I would like to know how to prevent this illness so that it does not affect me again. That would make me happy. (*Ndungu, 50, male, 1<sup>st</sup> interview, DCM*)

I would like to know what causes this illness so I can prevent it the next time. (*Waithera, 33, female, 1<sup>st</sup> interview, HHD*)

Patients also wanted to know what changes they could make to their lifestyle to prevent the illness from occurring again.

I would really like to know what would be 'good' and what I should avoid. At least I would know what can get me in trouble. (*Samueli, 75, male, 3<sup>rd</sup> interview, RHF with COPD*)

I have not been told about what I can do to prevent this illness or what type of food I should eat. I have not received any advice about this illness. (*Jaba, 65, male, 2<sup>nd</sup> interview, DCM*)

Other patients wanted to know more about their prognosis and how they could take care of themselves at home,

It would be good for a patient to know the progress (of their illness). In case something does happen, I should not be scared but know what to do at home....like first aid care. [*Ndungu, 50, male, 1<sup>st</sup> interview, dilated cardiomyopathy (DCM)*]

At the end of each interview, patients were asked whether they had any questions they would like to ask. Most were concerned about how their illness would affect their lives going forward. The following is a sample of questions posed by patients.

What will happen to me...will I get better? (*Shiru, 57, female, 1<sup>st</sup> interview, HHD/diabetes*)

How should I take my medication? (*Samueli, 75, male, 2<sup>nd</sup> interview, RHF with COPD*)

What happens to people like us? We cannot buy our drugs..how can we get help? What can we do so that we do not lose hope or feel like we have

been abandoned? We want to survive and get better. What help is there for us? (Njenga, 31, male, 2<sup>nd</sup> interview, RHF/COPD)

Where can I go to learn more about this illness? I would like to do this for myself. Maybe I can google...but if I can get it from a reliable source that would be better. (Mbui, 50, male, 2<sup>nd</sup> interview, DCM)

Will I ever heal from this? [Wangu, 35, female, 3<sup>rd</sup> interview HHD/diabetes/HIV (died two days later)]

Now that I have a heart problem, can I have a life partner? (Waithera, 33, female, 2<sup>nd</sup> interview HHD)

## **7.4 Better communication with health professionals**

Patients also spoke about how they would like information to be conveyed. Most expressed preference for patient-centred, honest, empathic communication with health professionals.

When you speak to the doctor and you understand each other that is good. It is better than the one who just talks to you. (Shiru, 57, female, 2<sup>nd</sup> interview, HHD/diabetes)

I really want to know the cause of my disease. Sometimes doctors can say things that can hurt you. They should always encourage their patients rather than discourage them. (Ruguru, 50, female, 3<sup>rd</sup> interview HHD)

Even in advanced stages of illness patients valued honest communication.

When I speak to them....they tell me that I am not going to get better. Sometimes I feel hopeless...but I know they are telling me the truth. They have nothing to gain from telling the truth. (Njenga, 31, male, 1<sup>st</sup> interview, RHF/COPD)

A few patients expressed a preference for private care where they could access patient-centred care. They felt that health professionals in public hospitals have heavy patient loads and may not have sufficient time and resources to offer the care they wanted.

The public hospital have very little time because of their workload. They just ask the important questions. A private doctor or a friendly doctor might be helpful. That is what I do. I go to a friendly doctor although he is not a cardiologist. (*Mbui, 50, male, 2<sup>nd</sup> interview, DCM*)

You know even if you are not that ill, the way the doctor speaks to you can make you feel worse. I would like the doctors to take their time, examine me properly so that I understand my condition and I can get the right treatment. Maybe next time I will go to a private hospital. They have better care and they treat you better. (*Waithera, 33, female, 2<sup>nd</sup> interview HHD*)

However, some, aware of the challenges at public hospitals empathised with staff at the public hospital.

It is not difficult to speak with the doctors.... It is just that the queue outside the hospital is so long and you feel for them. When it is your turn...you do not want to waste a single minute. (*Shiru, 57, female, 1<sup>st</sup> interview, HHD/diabetes*)

I would like to know more about my illness but the doctors have many patients to see. (*Bui, 18, female, 3<sup>rd</sup> interview, extra pulmonary tuberculosis*)

## **7.5 Better hospital environment**

Patients described an uncomfortable and difficult hospital environment.

They desired dignified care.

I felt they treated us badly. The bodies of people who had died were also treated badly. I wondered whether they would do the same to me when I died. I will not go back there again. I would rather go to a private hospital. (*Waithera, 33, female, 2<sup>nd</sup> interview HHD*)

Patients also expressed preference for compassionate care. Insensitive utterances from health professionals caused additional distress.

While on the ward, I noticed some nurses are very harsh. Instead of offering to help they shout at the patients. There was a day I was very weak. A nurse came and gave me my drugs. I asked her to pass a glass of water but she told me to get up and get it myself. Some nurses are nice, they give you your drugs and pass you a glass of water. It would be good

if they were more concerned about patients. (Bui, 18, female, 2<sup>nd</sup> interview, extra pulmonary tuberculosis)

Other patients were unhappy that the district hospital did not have the equipment needed to make a diagnosis, and that they had to go to other hospitals for further tests.

The care here is okay but it would be better if they had the 'machines' (echocardiogram machine) here. The doctors told us to go to another hospital to have the test done. I do not like this. Why should I spend more money elsewhere? (Riro, 38, male, 1<sup>st</sup> interview, HHD)

A few patients felt that the district hospital would benefit from renovation to create a comfortable physical environment.

The hospital is not in good condition. If the government can renovate this hospital, it would be good. These wards were built many years ago. It would be good if they can look into renovating the wards. (Jaba, 65, male, 1<sup>st</sup> interview, DCM)

## **7.6 Planning for the future**

Patients gave varying responses when asked 'what would you like to happen if you became worse?' Most patients said that they would prefer to return to the hospital for treatment. They felt that returning to the hospital would mean their treatment could be changed and possibly lead to a cure.

I would like to go back to the hospital and get other medication other than the one I am taking. I would like to get better. (Bui, 18, female, 2<sup>nd</sup> interview, extra pulmonary tuberculosis)

While most preferred to return to the hospital, Irungu described how he preferred to have his treatment at home as he felt observing other patients die in the hospital would be unfavourable.

I do not like staying in the hospital. I would rather be at home and take my medicine because at the hospital I will see a patient being brought in and die and I will worry that I am next. (*Irungu, 60 male, 2<sup>nd</sup> interview, HHD, diabetes*)

Other patients felt that there was nothing much that could be done if they got worse. They felt that death was the only other possibility.

There is no other treatment. It will only mean death. What can you do? If your time has come, your time has come (*Cege, 45, male, 2<sup>nd</sup> interview, right sided heart failure (RHF) from COPD*)

Although most patients openly expressed their preferences, one elderly patient was reluctant to share his views. He felt that events in the future are orchestrated by God and it would inappropriate to make future care plans.

I cannot think about that (future care) because it is only God who knows. Even if you think about it, you have no power. It is God who knows. (*Samueli, 75, male, 1<sup>st</sup> interview, RHF with COPD*)

## **7.7 Discussion**

Six key themes emerged which represent patients' perspectives on how to improve their care: getting a definitive diagnosis, affordable care, more information about the illness, better communication with health professionals, better hospital environment and planning for the future

### **A definitive diagnosis**

For many patients, recurrent exacerbations were a challenge. Patients felt disappointed when they failed to get better on treatment, which led them to believe that the right diagnosis had not been made. Most patients were unaware of the likely course of their illness, and lack of prognostic



information meant that patients were left on their own to understand their disease and make decisions about their care.

As discussed in previous chapters, the need for a cure pervaded patients' experiences from diagnosis to the last weeks of life. While this may have helped patients maintain hope, it also added to their distress. Seeking care at multiple health facilities increased patients' financial burden. Discontinuous care meant that patients often had to go through a costly process of re-diagnosis. For many, the possibility that their illness was incurable was hard to reconcile.

Conversely, patients with relatively stable symptoms felt satisfied with their diagnosis. Adequate symptom control was important to patients as it improved their quality of life, helped them get back to their life, and was a sign that a cure was possible.

### **Affordable care**

As the illness progressed, many patients were unsatisfied with the accumulating cost of care and regular access to health services was out of reach. Costs included clinic fees, diagnostic tests, and prescriptions. Only one patient had insurance cover, and all others self-paid, or made out of pocket payments. Care costs also included transportation, costs from days off work and need for additional help at home especially when patients become more dependent. Some patients coped by forgoing their clinic visits or renewing their prescriptions without visiting a health professional.

In Kenya, the proportion of the household budget spent on health care is highest in the poorest households (15%) compared to richest households (3%). Poorer households spend relatively five times more on health care than richer households (Chuma and Maina, 2012). A higher financial burden on

poorer families places them in a vicious cycle of poverty (Anderson and Grant, 2017). High health care costs mean patients are not able to access the care they need. This leads to worsening symptoms which limit their capacity to work which further reduces household income (WHO, 2005).

At the district hospital medicines supplies were irregular. Patients were often asked to purchase medicines from nearby private pharmacies that charged more than the public hospital. They were not allowed to leave the hospital, and had to rely on family members or relatives who came to visit to purchase the medicines they needed. They remained on the ward waiting for treatment while continuing to incur admission costs.

### **More information about the illness**

Throughout the study, patients remained unaware of the chronic nature of their illness. The sample list of questions patients posed at the end of the interviews is evidence of patients' significant need for information and the lack of communication that exists between patients and health professionals. Although patients did not ask questions, they wanted to know about the cause, treatment, and prognosis of their illness. Some perceived their illness as a benign acute condition and wanted to know how they could prevent a similar episode from recurring. Information on self-management strategies such as what lifestyle changes they should make was also important (Harding et al., 2008).

## **Better communication with health professionals**

As discussed in Chapter 6, patients lacked confidence initiating conversations with health professionals. However, underlying this, was a need for open, honest, patient-centred communication. Patients wanted to be brought into the medical encounter where they could engage mutually with health professionals (Gibbs et al., 2002). Where this was not possible, patients sought information from other sources including fellow patients on the ward. Even when conversations were difficult, they valued honest communication that would build trust. The need for supportive and compassionate communication was often unmet.

## **A better hospital environment**

A better hospital environment was important. Patients decried the lack of diagnostic equipment at the district hospital which meant they had to have tests done at private facilities. Only basic x-ray facilities were available at the district hospital. If advanced tests were required, the district hospital made arrangements with a private diagnostic centre to offer this service. Patients were expected to make out of pocket payments and were also charged an ambulance fee for transportation to the diagnostic centre. For example the cost of an echocardiogram and electrocardiograph was Ksh 9,500 (/£62)<sup>4</sup>. Patients who could not afford these additional tests while on the ward were requested to have these done at any private facility of their choice once discharged from hospital. Most were overwhelmed by these costs but felt they were necessary for their care.

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<sup>4</sup> **\*Cost/exchange rate during fieldwork (2014/2015).**

<sup>‡</sup> 82% of Kenyans are informally employed. 75% earn Ksh 1,000-9,000 per month

Patients also felt that the hospital environment denied them dignified care. They described negative attitudes from health professionals, who were unfriendly and lacked empathy, which made them feel as though their needs were dismissed (Ojwang et al., 2010). Poor organizational management at district hospitals has been found to lower staff motivation which has a negative effect on the quality of care (Mbindyo et al., 2009). Patients were also concerned with the way the bodies of those who had died were treated. They feared they would undergo similar treatment, and preferred to receive care at a private hospital. The physical state of the district hospital was a significant concern and patients desired a comfortable environment. Hospital wards offered little privacy as sometimes patients had to share beds and there were no curtains to separate cubicles.

## **Planning for the future**

Most patients preferred to return to the hospital if they got worse. The hospital was viewed as the place they could be cured of their illness or at least receive treatment for their physical symptoms. Nevertheless, a few patients associated the hospital with death and dying and preferred to be at home during their last weeks of life.

As discussed in Chapter 6, African communities have multiple understandings of death and dying. Although death is considered to be in the hand of God, all measures should be taken to preserve life. These measures include seeking curative therapy in advanced stages of illness even when treatment offers no additional benefit.

Discussing end of life preferences for middle-aged or younger people is often discouraged. However, older people may share their wishes, by giving verbal instructions to their families regarding management of property and money. Ageing is viewed as a normal phenomenon that eventually leads to death (Ekore and Lanre-Abass, 2016) and is different from an illness, which may be perceived to have a spiritual cause and can be cured by God. It would be inappropriate to speak about death if there is a belief that God can intervene and cure. This religious view of death and dying is exemplified in a review of 356 obituaries published in Kenya newspapers. Most announcements had religious undertones in which death was regarded as God's will (Ondimu, 2014).

## **Chapter 8 : Integration of research findings, recommendations for practice, policy and future research**

This chapter is presented in five parts. The first section begins by positioning key findings of this research within a set of overarching themes: (i) transition from health to illness, (ii) uncertainty of living and dying with heart failure, (iii) lack of information and poor communication with health professionals. Each theme is supported by a theoretical framework. The second part of this chapter describes the strength and limitations of this study, and the third part provides recommendations for practice and policy. The fourth section presents implications for future research. This chapter concludes with a closing statement.

### **8.1 Integrating research findings**

#### **8.1.1 Transition from health to illness**

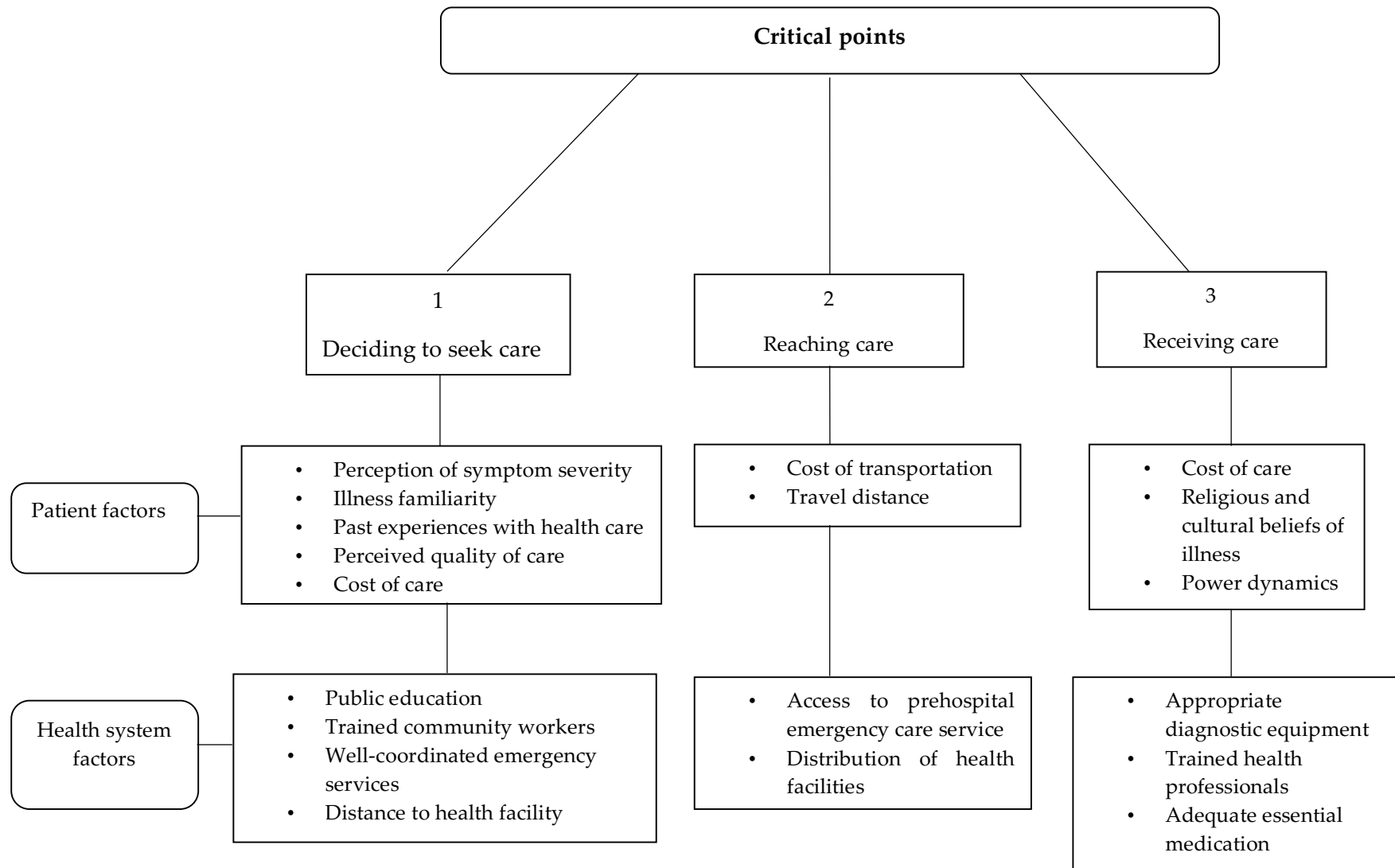
This theme highlights three significant issues. First, it draws attention to patients' experiences from the time they become aware of their symptoms to when they obtain a diagnosis of heart failure and begin treatment (Andersen and Cacioppo, 1995). Second, it reveals how patients' illness experience influences care seeking. Third, it emphasizes the challenge of obtaining a diagnosis of heart failure in Kenya.

In SSA, several theoretical frameworks have been suggested to explain critical time points from when a patient first experiences physical symptoms to when they access quality care. In a review of obstetric care, Thaddeus and Maine (1994) suggest three key time points: (i) deciding to seek care (ii)

getting to a health care facility and (iii) receiving appropriate care in a health facility. Similarly, Grant (2013) identifies three critical time points in accessing palliative care: (i) determining that patients are dying (ii) receiving the appropriate level of care including access to pain relief (iii) getting to the right place of care whether at home or the hospital. Calvillo et al. (2015) also identify a comparable three-staged approach to accessing emergency care in low and middle-income countries.

Drawing from results of this study and theoretical frameworks on delays to accessing quality care in SSA, Figure 15 overleaf details three critical points for the delay in health care seeking for patients with heart failure in Kenya. This diagram is a framework to support understanding how patient and health system factors may hinder access to a timely diagnosis of heart failure and prompt initiation of effective care.

**Figure 15:** Critical points to appropriate diagnosis and treatment of heart failure in Kenya





Several factors influenced patients' initial decision to seek care. Patients with distressing symptoms perceived their illness as severe, which triggered an early decision to seek care. In particular, acute breathlessness caused significant anxiety (Anderson et al., 2001 ; Boyd et al., 2004 ; Gysels and Higginson, 2011) and prompted the need for emergency services.

Conversely, symptoms with gradual onset were harder to recognise which meant patients remained unaware of a life-threatening illness. (Sethares et al., 2014 ; Evangelista et al., 2000). Literature from SSA notes that patients with life-threatening illness present late when the disease is already in advanced stages (Onyeka, 2011 ; Kimani et al., 2017). In a study of 1515 new diagnoses cases of heart failure in Nigeria, Ojji et al. (2013) found that 80% of patients presented in advanced stages (NYHA III/IV) of illness.

Other studies have identified similar factors influencing delay in diagnosing heart failure. Sudden onset breathlessness, fluid retention or chest pain shorten delay to diagnosis compared to slowly progressing symptoms that can be self-managed at home (Cowie et al., 2014 ; Evangelista et al., 2000). Failure of primary care physicians to correctly diagnose heart failure, and lack of emergency ambulance transportation, may delay diagnosis and early initiation of effective treatment (Gravely-Witte et al., 2011). Depression and other negative emotions may also hinder patients from assessing symptoms requiring urgent care (Cowie et al., 2014).

Understanding factors hindering a timely and definite diagnosis of heart failure is relevant to patient care (Cowie et al., 2014). A rapid diagnosis means that patients can benefit from effective care that integrates disease modifying treatment with early palliative care, and aims at optimising symptom control and improving quality of life. Early palliative care seeks to enhance communication between patients and health professionals which

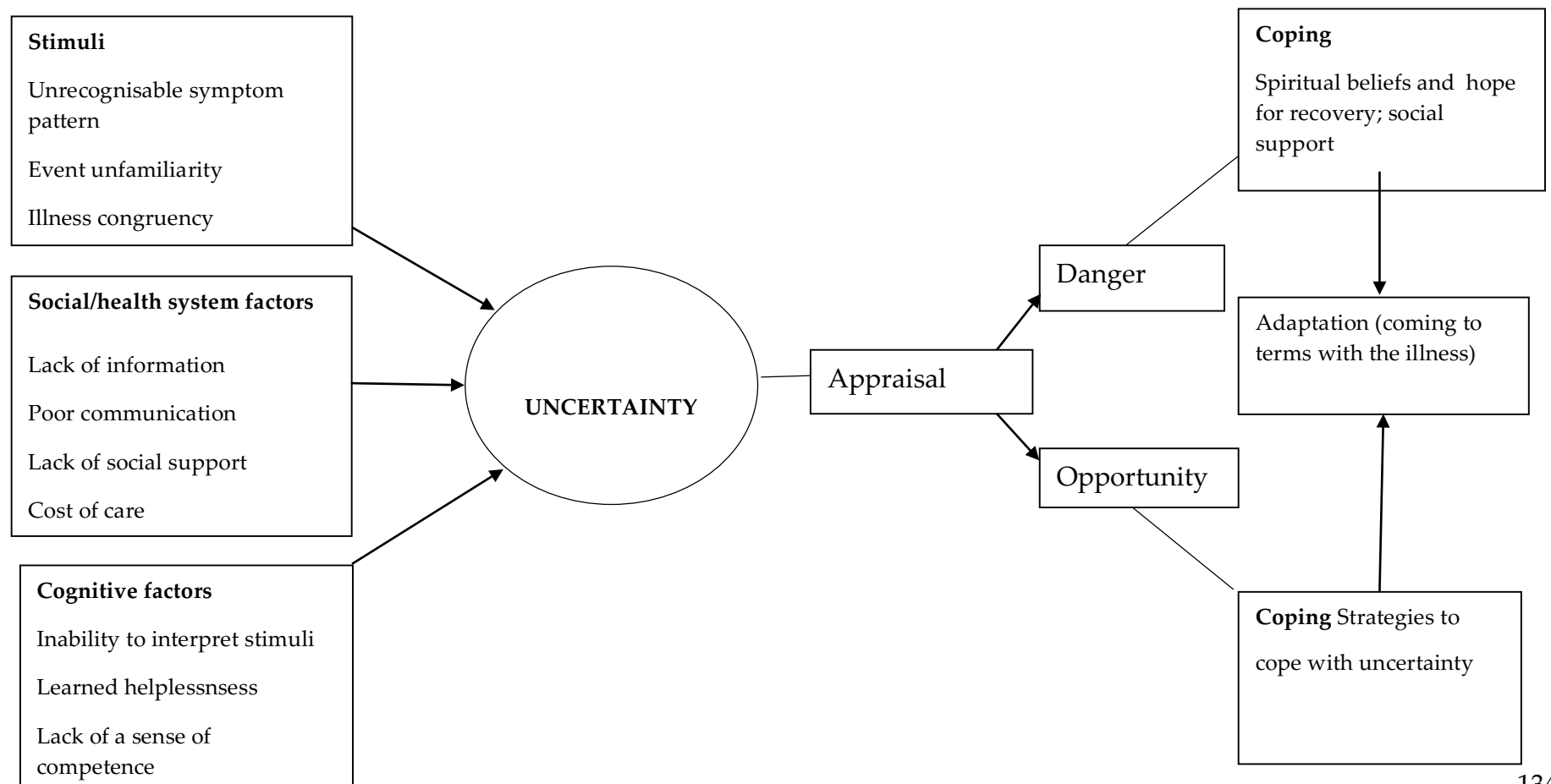
means patients can benefit from timely identification of needs and treatment goals. Additionally, early palliative care has been shown to enhance patient outcomes by improving survival, minimizing the burden of negative symptoms (Zimmermann et al., 2014 ; Temel et al., 2017 ; Temel et al., 2010), and reducing the number of emergency room visits and hospital admissions (Hui et al., 2014). A reduction in hospital visits may lessen the financial burden associated with chronic illness.

### **8.1.2 Uncertainty of living and dying with heart failure**

Uncertainty underlay patients' experiences from diagnosis to death. In addition to physical, social, psychological, spiritual, and financial problems, patients struggled to make sense of their illness. Drawing upon Mishel's theory of uncertainty, figure 16 on the next page proposes a framework of uncertainty for patients living and dying with heart failure in Kenya.

In the course of their illness, most patients expected to recover but were overwhelmed by a chronic unpredictable condition. Poor communication from health professionals intensified uncertainty, as patients had little understanding of their illness, or what to expect in the future. Furthermore, patients who felt disempowered rarely asked questions which limited their access to essential information. Financial constraints from accumulating health care costs caused patients to stay away from the care and information they needed most. Patients' expectations of cure resulted in multiple self-referrals that led to discontinuity in care. Medical records were not centralised and caused inconsistencies in patient care. Although spiritual beliefs and social support helped patients cope with uncertainty, these were pressured by a chronic and unpredictable illness (Kimani et al., 2016b).

**Figure 16:** Framework of uncertainty for patients living and dying with heart failure in Kenya. Adapted from Mishel (1988) and Wright (2009) Permission to reproduce obtained



The theme uncertainty is also reported in other studies. In a narrative review of qualitative studies conducted in the US, Canada, Sweden and New Zealand to explore the experience of living with heart failure, Jeon et al. (2010) found that uncertainty was prevalent and associated with negative emotions such as fear, depression and anxiety. Older patients have been found to cope better since they view uncertainty as an inevitable part of life (Winters, 1999 ; Dudas et al., 2013). In Kenya, younger patients experienced more anxiety as they worried about supporting their families and meeting society's expectation of remaining active and economically productive. These findings are similar to those of Rodriguez et al. (2008) who found that financial concerns caused considerable distress in younger people. Health services in Kenya, organised around acute episodic care, may be ill-equipped to cater for patients' chronic needs (Samb et al., 2010). Failure to identify and respond to patients' multidimensional problems, and plan for their care, may deepen uncertainty further. Uncertainty is also highlighted in other organ failure diseases such as liver failure (Kimbell et al., 2015), end stage kidney disease Parvez et al. (2015) and COPD (Small and Graydon, 1993 ; Pinnock et al., 2011).

According to Mishel (1981) four factors characterise uncertainty: (i) ambiguity –which is a patient's self-assessment of the vagueness of their illness (ii) unpredictability – when present illness experience fails to match past experiences (iii) lack of information (iv) and complexity which refers to approaches to treatment and care which are difficult for patients to understand (Mishel, 1981). Other forms of uncertainty identified in the literature include system uncertainty (uncertainty about the competence of health professionals and access to appropriate care) and personal uncertainty (uncertainty about how illness affects one's personal relationships and future

goals) (Han et al., 2011). These forms of uncertainty were evident from patients' descriptions and questions posed to the researcher at end of the interviews.

### **8.1.3 Lack of information and poor communication with health professionals**

From diagnosis to last days of life, patients described the challenges of communicating with health professionals. Although this theme is highlighted in previous sections of this chapter, it is a significant issue that warrants separate discussion to allow for a nuanced examination of its implications.

Although patients expressed a need for information about the nature of their illness, treatment and expected outcomes, these issues were rarely discussed. Lack of confidence in initiating conversations, spiritual beliefs about the role of health professionals, fear of reproach, limited patient autonomy and power dynamics between patient and their health care providers limited discussions. Additionally, patients' perceptions about health professionals' unwillingness to speak about death and dying prevented sensitive topics from being discussed. In the absence of credible information, patients relied on media sources, and fellow patients to meet their information needs.

These findings reflect those of previous studies. Although patients with heart failure prefer open and honest communication, they find it difficult to approach health professionals (Lowey et al., 2013). Patients fear rebuke for making enquiries and prefer health professionals to take the lead in decision-making. Information on prognosis, treatment regimens, and how they should respond to emergencies are of great concern to patients (Horne and Payne,

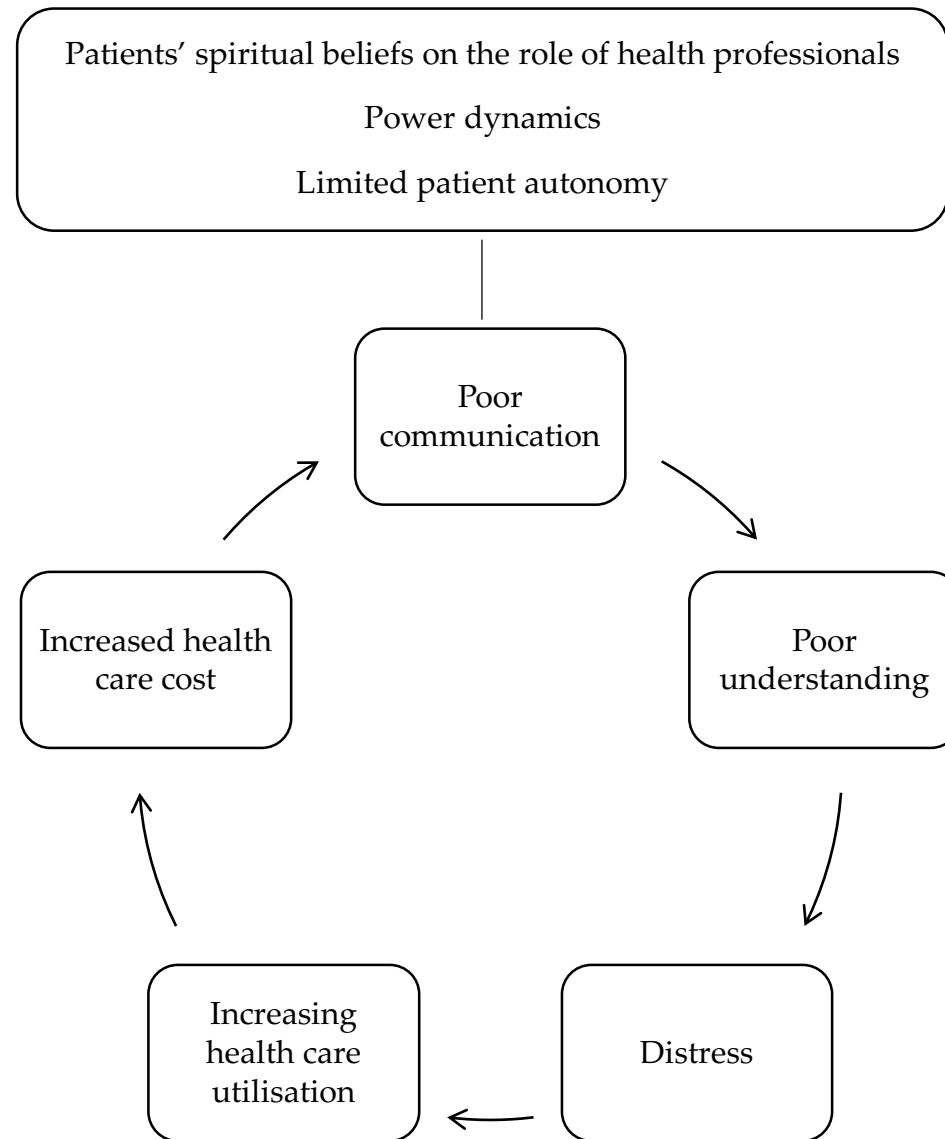
2004). In SSA, Selman et al. (2013) found that patients with HIV failed to initiate communication due to their perception of the help health professionals could offer. Other possible barriers to communication include the cost of care including indirect costs such as transportation, which may limit opportunities for accessing reliable information. Declining cognitive function may reduce a patient's ability to remember which questions ask during hospital appointments (Rogers et al., 2000). Also, care focussed on achieving cure may overlook psychological and spiritual needs which may cause patients to feel neglected and disempowered to initiate communication with health professionals (Harding et al., 2008).

The aim of effective communication is to exchange information, improve identification of patients' needs, support interpersonal relationships and involve patients in shared decision making (Ha and Longnecker, 2010). Ong et al. (1995) suggest a three-pronged theoretical framework explaining the role of doctor-patient communication on patient outcomes. The three parts of this framework include: (i) *background variables* such as culture and the nature of doctor-patient relationship and how they influence (ii) *communicative behaviour (affective or task focused)* and how this affects (iii) *patient outcomes*.

The results of this study show how background factors such a spiritual beliefs, power dynamics and level of patient autonomy influenced how health professionals communicated with patients (Figure 17 overleaf). Poor communication produced a cyclic effect on patients' experience. Patients' lack of understanding about their illness increased uncertainty. Patients who were distress utilised more health services which increased health care costs. Similarly, Grant et al. (2004) propose that patients' unmet needs may cause greater distress and increase the use of health services. Accumulating costs kept patients away from accessing health services and further limiting

opportunities to communicate with health professionals. Borrowing from Ong et al. (1995) model of doctor-patient communication and work by (Grant et al., 2004), figure 17 on the next page is a framework representing how poor communication affects the experience of patients with heart failure in Kenya.

**Figure 17:** Framework of the effect of poor communication on the experiences of patients with heart failure in Kenya





## **8.2 Study strengths and limitations**

### **Strengths**

This is the first serial interview study to explore the experiences of patients living and dying with heart failure in Kenya. These findings add to the growing body of literature exploring the experiences of patients with advanced life-threatening illness in SSA (Namukwaya, 2014). This work provides geographic and ethnic diversity to previous similar qualitative research conducted predominantly in European countries (Hopp, 2010). This study also advances understanding of three overarching themes explaining the experience of patients with heart failure in Kenya namely transitioning from health to illness, uncertainty, and doctor-patient communication.

The findings of this research also broaden the evidence base on heart failure in SSA. As mentioned in Chapter 2, most studies conducted in SSA have employed quantitative methods. This study adds a rich and unique narrative to existing knowledge and provides a more nuanced understanding of heart failure in this region. A longitudinal qualitative approach allowed for in-depth exploration of patients' experiences and facilitated the generation of rich accounts that may not be possible with quantitative approaches. The longitudinal nature of this study encouraged trusting relationships to develop between the researcher and participants which supported discussion of sensitive topics (Murray et al., 2009).

## **Limitations**

The following limitations may influence the interpretation of these findings.

First, although this study sought to recruit participants from diverse sociodemographic, religious and cultural background residing in central Kenya, these finding may not be generalizable to other regions in Kenya, Africa and beyond.

Second, patients who were very ill or cognitively impaired were excluded from taking part in this research. However, this was mitigated by the longitudinal nature of this study, which facilitated the exploration of patients' experiences as they progressively declined. Additionally, interviews with carers allowed for examination of issues and concerns that were significant to patients in the last days of life.

Third, attempts were made to select patients reflecting the epidemiology of heart failure in the region. Although rheumatic heart disease (RHD) is a leading cause of heart failure in SSA, this group of patients is not fully represented in this sample. Patients with RHD at the district hospital were in the paediatric age group and were ineligible for recruitment.

Finally, participants were recruited from a district hospital in Kenya, and their experiences might differ with those receiving care at other levels of the health care system.

Additional opportunities and challenges posed by this research are discussed further in a reflexive account in Chapter 9.

## **8.3 Recommendations for practice and policy**

The findings of this study aim to support policy makers, researchers, cardiologists and other health professionals involved in the care of patients with heart failure in Kenya. Table 6 on page 144 summarises recommendations from this study.

### **8.3.1 Supporting timely and accurate diagnosis of heart failure**

This research identified patient and health system factors that cause delays in diagnosis and treatment of heart failure. Strategies aimed at educating the public, health professionals, and community health workers to improve recognition of heart failure symptoms may reduce unnecessary delays.

Television, radio, print, social media, and community barazas (meetings) may be used to deliver simple and accurate messages about heart failure.

Staff at lower level facilities should be trained in heart failure management.

Training may involve task shifting to delegate diagnosis and treatment of heart failure to less specialised health care workers to address the shortage of well-trained health professionals (Cowie et al., 2014 ; Ponikowski et al., 2014).

Public education and training health workers may help to reduce the uncertainty associated with heart failure by making symptoms more familiar and supporting health workers to identify patients' needs early

To adequately respond to health system factors causing delay in diagnosis and treatment of heart failure substantial changes are required. These changes are complex, and it may not be possible to implement them simultaneously as they require the significant mobilization of resources (financial and human) and political goodwill (Calvello et al., 2015). The

effective diagnosis and management of chronic diseases rely on a well-functioning health care system and equitable access to care. Efforts to strengthen health systems aimed at delivering: safe and effective health services, a responsive and efficient health workforce, robust health information system, equitable access to essential medicines, well-functioning health financing system and responsible leadership and governance should be broadened to support timely and accurate diagnosis and management of heart failure. Lessons learned from improving the diagnosis and treatment of patients with other conditions such as HIV/AIDS could also benefit those with heart failure (Samb et al., 2010). Lessons from this study may also be applicable to other illnesses such as advance lung, liver or renal disease.

**Table 6:** Recommendations for practice and policy for patients living and dying with heart failure in Kenya

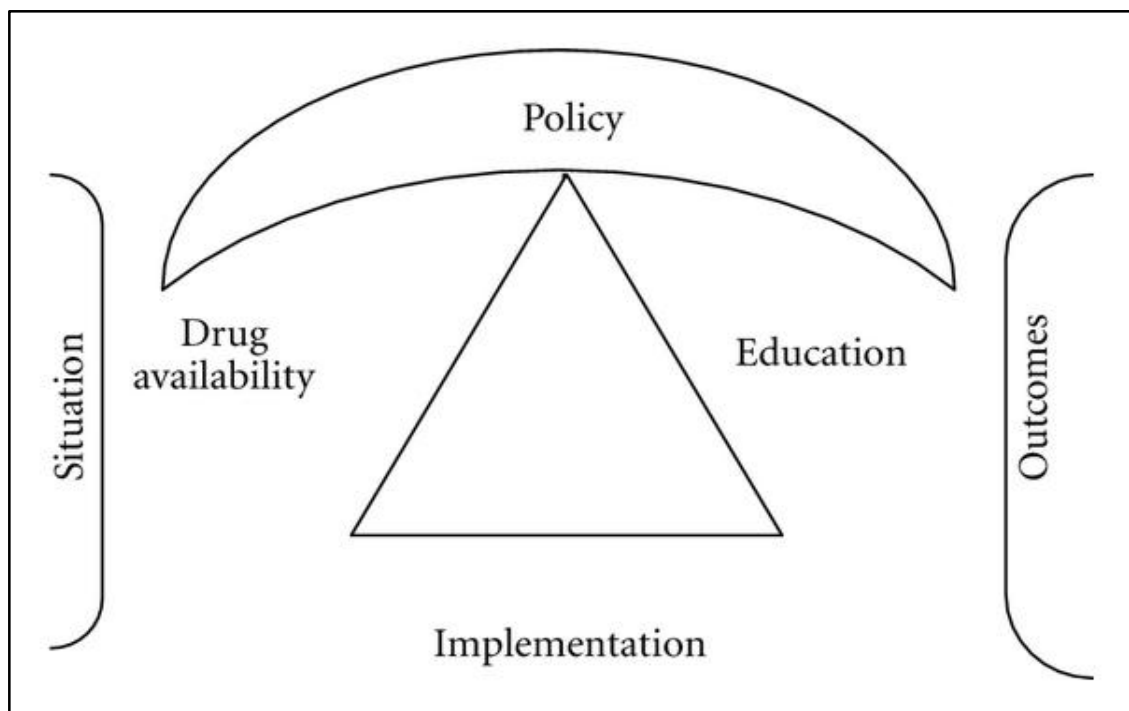
<b>1. Diagnosis of heart failure</b>	<ul style="list-style-type: none"> <li>• Educate public and community health workers to recognise symptoms and signs of heart failure</li> <li>• Task shifting and training less specialised staff at basic level facilities to diagnosis and manage heart failure or refer</li> <li>• Strengthen health systems</li> <li>• Leverage lessons from other health programmes (HIV/AIDS)</li> </ul>
<b>2. Holistic care</b>	<b>National policies</b> <ul style="list-style-type: none"> <li>• Policies should include the strategies for primary prevention, early detection, prompt initiation of disease modifying therapy and the early integration of palliative care</li> <li>• Support early palliative care to be incorporated with chronic disease management</li> </ul>
	<b>Adequate drug availability</b> <ul style="list-style-type: none"> <li>• Improve access to essential heart failure medicines such as furosemide</li> <li>• Support legal frameworks and drug supply chain systems</li> <li>• Leverage lessons from Uganda on task shifting for essential medicines</li> </ul>
	<b>Education and training</b> <ul style="list-style-type: none"> <li>• Support three tiered approach to palliative care education and training: basic, general and specialist training</li> <li>• Utilize existing training manuals published by APCA and KEHPCA</li> </ul>
	<b>Multi sectoral partnerships</b> <ul style="list-style-type: none"> <li>• Advocate for community engagement through the 2006 Community Health Strategy</li> <li>• District health management team to work with community health volunteers to engage with communities about supporting people with advanced illnesses such as heart failure</li> </ul>
<b>3. Lack of information and communication with health professionals</b>	<ul style="list-style-type: none"> <li>• Support strategies to empower patients</li> <li>• Promote patient-centred approaches to care</li> <li>• Societal and health care policies to address financial and social imbalances in power between patients and health professionals</li> </ul>

### 8.3.2 Holistic care for patients with heart failure in Kenya

The findings of this research reveal that patients with heart failure would benefit from a holistic approach to care. Patients experienced a substantial multidimensional symptom burden against a backdrop of progressive decline. Services that integrate chronic disease management with palliative care can cater to patients multidimensional needs (Stjernsward et al., 2007).

The World Health Assembly resolution provides a blueprint for the integration of palliative services (WHA, 2014). It echoes the public health strategy on palliative care as suggested by Stjernsward et al. (2007) (Figure 18 below).

**Figure 18:** Public Health Strategy for Palliative Care. Stjernsward (2007) Reprinted with permission



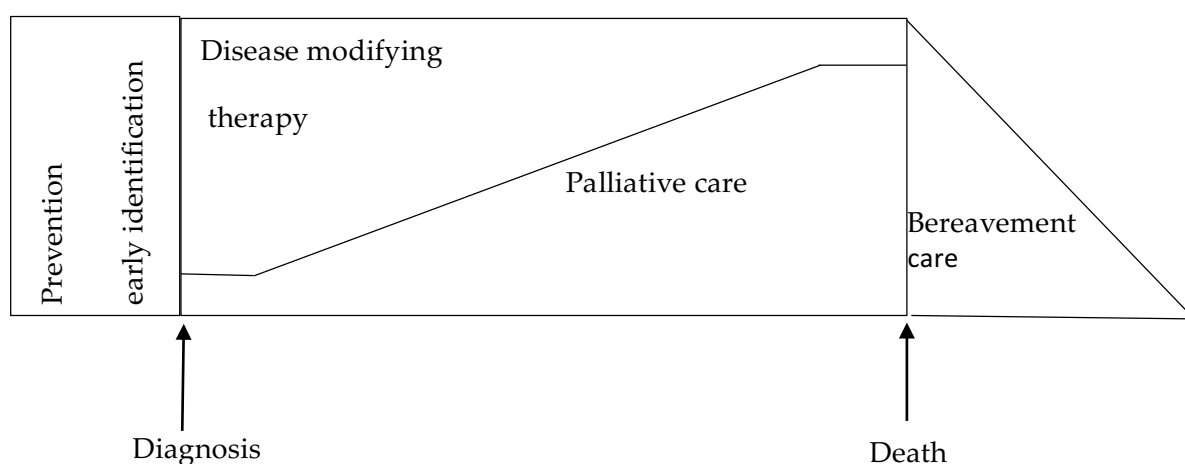
The resolution urges the strengthening of palliative care along the following pillars (i) development of appropriate policies which aim to integrate evidence-based palliative care across the continuum of care (ii) education and training for healthcare professionals (iii) update essential medicines lists and review policies for controlled medicines (iv) build multisector partnerships. These should be supported by monitoring and evaluating national palliative care actions as part of global non-communicable disease control plans and providing adequate financial funding to support the integration and implementation of palliative care in national programmes.

### **National policies**

Kenya is yet to develop a national policy to guide palliative care for patients living and dying with heart failure. However, as noted in Chapter 1, the national strategy for the prevention and control of non-communicable diseases identifies palliative care as a tertiary prevention strategy to be implemented when patients have lost their functioning capacity (GOK, 2015). This strategy resembles the old concept of palliative care designed for patients dying of cancer in which palliative care is synonymous with terminal care. The results of this study show that patients have multidimensional needs early in their illness and would benefit from an approach that incorporates early palliative care with chronic disease management. Early palliative care would help address challenges around communication which caused continual uncertainty as identified in earlier sections of this chapter. Early palliative care is a modified approach to the phased version, discussed in Chapter 1, in which palliative care and disease modifying treatment start close at diagnosis. At the end of life, palliative care

plays a more significant role as disease-modifying treatment continues (Fig 19 below)(Gibbs et al., 2002).

**Figure 19:** Proposed model the integration of palliative care in Kenya. Source: Adopted from Gibbs (2002). Permission obtained



Borrowing from the principles of integrating palliative care into the national cancer health policies, a national heart failure policy should include the following components: primary prevention, early detection, prompt initiation of disease modifying therapy and palliative care (Stjernswärd et al., 2007).

Primary prevention strategies include the adoption of healthier diets, regular exercise and reduction of harmful habits, such as smoking and unhealthy levels of alcohol which have been identified as significant risk factors for cardiovascular diseases (WHO, 2014a). Appropriate medications for those at high risk of developing heart failure should be included in national policies. Prevention strategies should also include greater public awareness of heart failure especially symptoms that warrant urgent medical care. Future work



on identifying those with highest risk at developing heart failure is needed (Ponikowski et al., 2014).

### **Adequate drug availability**

Providing essential medicines is vital for the successful integration of palliative care. The 2015, WHO Model List of Essential Medicines recommends two classes of drugs for heart failure: (i) diuretics to reduce fluid retention (furosemide, hydrochlorothiazide, spironolactone) and (ii) drugs to control heart rate and rhythm (digoxin and bisoprolol) (WHO, 2015).

Although furosemide is commonly prescribed in heart failure (Sera et al., 2014) it is absent from the essential drug list for palliative care (WHO, 2013). Diuretics and in particular furosemide are the mainstay of heart failure treatment (Shah et al., 2004). Improved drug supply systems are needed to improve access to essential medicines which may go a long way to not only improve physical symptoms but costs associated with repeat admissions. Policies that aim to improve the accessibility and affordability of essential medicines are required. Adequate funding to procure essential drugs, strengthen supply chains and support financial incentives such as eliminating taxes on essential medicines are needed (Mendis et al., 2007).

In many parts of Africa, access to palliative care medicines such as morphine remains a significant challenge. Weak legal and regulatory frameworks for poor supply chain systems and misconceptions about the risk of using opioids contribute to challenges in accessing morphine (O'Brien et al., 2013). Lesson on how to improve access to essential medications can be borrowed from Uganda's experience in improving access to morphine. Less specialised health workers such as clinical officers and nurses have been trained to

prescribe morphine at no cost to patients (Jagwe and Merriman, 2007 ; Kimani et al., 2017). A similar task shifting approach may be considered for improving access to essential medicines for patients with heart failure.

## **Education and training**

Correctly identifying patients who need palliative care is essential to providing effective care. To improve the capacity of health professionals to identify the needs of patients with heart failure, basic training in palliative care needs to be incorporated in undergraduate and postgraduate medical education. The Integrate Palliative Care Curriculum Toolkit identifies a three tiered approach to palliative care training : (i) *basic training in a palliative care approach*: which is part of undergraduate medical training, in-service training for health care providers and caregivers at the primary health care level (ii) *general palliative care training*: offered to undergraduate and postgraduate training by primary care professionals and specialists (iii) *specialist training*: offered to palliative care specialists to care for complex cases as well as support mentorship (Snell et al., 2016). Palliative care training should focus on multidimensional symptom management, ethical and legal aspects of palliative care, communication skills, and teamwork. Training can build on cross-cutting themes in existing curricula by strengthening existing courses to include aspects of palliative care and offering separate palliative care teaching and elective courses. Manuals and guidelines developed by the African Association of Palliative Care and KEHPCA<sup>5</sup> focused on access to essential medicines <sup>6</sup>, pain management<sup>7</sup>, advocacy<sup>8</sup> as well as a core

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<sup>5</sup> Kenya Registered Palliative Care Nursing; National Palliative Care Training Curriculum for HIV & AIDS, Cancer and other Life-threatening Illnesses; Legal Aspects in Palliative Care

<sup>6</sup> Guidelines for Ensuring Patient Access to, and Safe Management of, Controlled Medicines (2010)

<sup>7</sup> Beating Pain: A Pocket Guide for Pain Management in Africa (2010)

<sup>8</sup> Successful Advocacy for Palliative Care: A Toolkit (2011)

curriculum for PC <sup>9</sup>and effective teaching methods<sup>10</sup> are readily available to aid in education and training (APCA, 2014).

## **Multisectoral partnerships**

Care for the dying is everyone's business (Kellehear, 2013). The value of communities fully participating in their care is a well-recognised principle of the Alma Ata declaration on primary health care (WHO, 1978) and the Ottawa Charter for Health Promotion (WHO, 1986).

The World Health Assembly (2014) advocates the integration of palliative care at the primary care level. Primary health care is the central component of a country's health system and is the initial level of contact with the health system for patients, families and, communities. Primary health care helps individuals and communities to be active participants in health care from the planning stage to implementation of health interventions (WHO, 2008). It also supports health professionals to collaborate with community health workers and trained traditional practitioners to respond to peoples' needs. Primary health care also aims to build partnerships with health related sectors such as education and communication which are involved in social and economic development to promote a wider societal response to health care (WHO, 1978).

The World Health Assembly resolution notes that poor integration of palliative care into health and social care leads to inequitable access to palliative care services (WHA, 2014). Community engagement for palliative

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<sup>9</sup> *Palliative Care Core Curriculum (2012)*

<sup>10</sup> *Effective methods of teaching palliative care (2014)*

care aims to inform and empower people to identify and discuss their needs with the support of health professionals. It seeks to place people at the centre of their care, provide information (about illness, death and dying), offer social support to people and communities and help people adjust and cope with their illness (Kellehear, 1999).

In Kenya, the Community Health Strategy developed in 2006 informs how households and communities can take on a more central and active role in health promotion, disease prevention, care seeking, governance of health systems and claiming their rights to access equitable, quality and cost effective healthcare (GOK, 2006). In this plan, the district (sub-county) health management team is responsible for planning, implementing and supervising community services. Community services are supported by volunteer community health workers who are linked to the district facility by a trained community health extension worker (McCollum et al., 2016). The WHO guide for the planning and implementation of palliative care services also identifies the district hospital as a strategic point for coordinating and organising palliative care services and linking with communities (WHO, 2016). In an evaluation of palliative care service models in Kenya and Malawi, Downing et al. (2015) found that district and community based services are well placed to offer patient centred services to people with complex needs. Community services were flexible in responding to patients' dynamic illness trajectory which benefits to people with chronic illness.

Although community strategies also increase access to equitable and affordable services, they require significant commitment to training, financial support, and overall supervision and wider political support for national frameworks and policies to ensure their sustainability (Berman et al., 1987).

### **8.3.3 *Improving communication with health professionals***

Power dynamics, spiritual beliefs, and limited patient autonomy hindered effective communication. Strategies which empower patients to take part in decision-making, identify personal goals, and seek information can improve communication (Aujoulat et al., 2007). Patient-centred care based on a biopsychosocial approach to illness may support patients to identify and express their multidimensional needs as well as foster trust and improve communication with health professionals (Kaba and Sooriakumaran, 2007 ; Dudas et al., 2013). Furthermore, wider societal and health care policies which promote patients' rights and subsidize the cost of health care may help address imbalances in financial and social power between patients and health professionals (Goodyear-Smith and Buetow, 2001 ; Gibson, 1991).

## **8.4 Implications for future research**

From this thesis, the following areas have been identified for future research

- Focus group research to discuss the findings of this study with key stakeholders such as policy makers, cardiologists and other health professionals to identify priorities for patient care and to develop a national practice guideline to direct timely accurate diagnosis and multidimensional care of patients with heart failure.
- Uncertainty was an important theme identified in this research. Future studies should evaluate cost-effective, accessible and acceptable approaches to providing information to patients, carers, and the

general public. Further work should also explore cognitive and behavioural strategies that help patients cope with and adapt to uncertainty.

- This study recruited patients residing in central Kenya majority with a Christian religious affiliation. Qualitative studies to explore the experiences of heart failure patients of different ethnic, religious and socioeconomic backgrounds in Kenya should be conducted.
- Rheumatic heart disease is a leading cause of heart failure in SSA but was not fully represented in this sample. Future studies should aim to incorporate the experiences of this patient group.
- This study recruited patients admitted to a district hospital in Kenya. Given that patients can access care at any level of the health care system, the experiences of patients accessing care at national referral hospitals offering specialised care should be explored.
- This study focused on patients' experiences. Although carers were recruited and participated in this research, their experiences were not explored. Qualitative studies exploring the experiences of carers and health professionals are needed to inform heart failure policy and practice.

## **8.5 Concluding statement**

This study explored patients' experiences of living and dying with heart failure in Kenya. Specifically, it sought to understand patients' experience with their illness, their experience with care and their views on how their care can be improved. This study revealed significant challenges in obtaining a diagnosis of heart failure and identified patients' multidimensional distress from the time of diagnosis up to the last days of life. Underlying this multidimensional distress was significant uncertainty compounded by patients' lack of information about their illness and poor communication with health professionals.

In a review of global perspectives of end of life care, Singer and Bowman (2002:8) pose the following question: 'Is a focus on quality end of life care justifiable when many deaths in developing countries are preventable?'

Indeed, the majority of deaths in Kenya and other SSA countries are caused by communicable diseases, and maternal and child health conditions, most of which are preventable (Mathers and Loncar, 2006).

Despite the challenges that persist for communicable disease control and improving access to better maternal and child health care in SSA, the reality of changing disease patterns from a growing burden of chronic diseases can no longer be ignored. A rethink of how to orientate and organise services to meet the complex, dynamic and multidimensional needs of people with chronic illness is required.

This study provided evidence from Kenya on how to improve care for people with heart failure. Strategies aimed at enhancing access to timely and accurate diagnosis, integrating holistic care with chronic disease management, improving patients' access to information and promoting

better communication with health professionals are needed. This research also highlights the importance of increasing efforts to develop and strengthen country health systems.



## **Chapter 9 : Reflections on conducting the research in Kenya**

This chapter presents an overview of my experience conducting this research in Kenya. In the following sections, I discuss the opportunities and challenges I encountered in the course of this research project.

### **Opportunities and challenges**

#### **Ethics approval in Kenya**

To conduct fieldwork, I needed clearance from two departments: (i) the research governance committee at the Centre for Population Health Sciences at the University of Edinburgh and (ii) the research ethics committee in Kenya. At the end of the first year of my Ph.D., I applied for ethics clearance at the University of Edinburgh and received approval two months later.

The process in Kenya was less straightforward. It took four months from the time of application to when I received ethical approval. One challenge was the lack of clarity about where to apply for ethics approval. In reviewing research ethics in developing countries Zumla and Costello (2002) note similar challenges and identify the lack of clear regulatory frameworks to guide health care research.

At the time, four institutions could grant ethical approval in Kenya: two were universities, and the other were national organisations involved in research. Initially, I was advised (by Kenyan colleagues) to lodge my application with one of the national organisations since I was a Kenyan studying abroad intending to conduct research in the country (NCST, 2005:2). I submitted my application through the organisation's website and was informed that it

would take two weeks to receive feedback. However, several weeks later I was yet to receive any feedback. After numerous unsuccessful inquiries, I was advised to resubmit my application at one of the local universities. I received ethical approval two months later.

### **Conducting fieldwork in Kenya (2014 -2015)**

In 2013, health care in Kenya was devolved from the national government to 47 county units. The backdrop of this was the approval of a new constitution (in 2010) which decentralised most public services. Decentralised health care meant that hospitals, up to the county level, were managed by devolved units while referral hospitals were operated by the national government.

These changes brought about challenges. For instance, the process of devolution occurred quickly with little time to make plans on how to manage the healthcare workforce. Before devolution, the national government employed health professionals working in the public health care system. However, with a devolved system, it was unclear whether health workers in public service were employees of national government or the county units. Problems with reorganising the health workforce caused confusion, which lowered staff motivation.

In the course of conducting fieldwork, there were two industrial strikes at the district hospital: Dec 2014 – Jan 2015 and in August 2015. Both related to issues around remuneration. Recruitment slowed during these strikes as patients stayed away from the hospital and hospital staff had little motivation to work or engage in the research. Once an industrial strike ended, it took at least two weeks for patient flow at the hospital to return to normal. To maintain staff motivation, several meetings were planned with

recruiting staff to discuss their challenges. While these meetings did not solve their concerns about remuneration, they were appreciated.

### **Longitudinal qualitative methods**

There are no set time limits for engaging with longitudinal qualitative studies. The strength of longitudinal qualitative methods is that it incorporates time as a fundamental aspect of data analysis and evaluates how participants experience change (Saldana, 2003:3). Furthermore, the retrospective and prospective nature of these methods allow participants to reflect back in time and also describe events prospectively as they occur which supports a more nuanced understanding of events over time.

Longitudinal qualitative methods also allow for flexibility (Holland et al., 2006). For example, interview timings were flexible which facilitated the capture of change as it emerged. A flexible interview schedule was appreciated by participants as they felt their situation was understood (Cotter et al., 2002). This flexibility helped limit attrition.

Although longitudinal methods are beneficial in exploring change over time, they present several challenges. There was a significant risk that patients would either become too unwell to take part or die before the end of the study period. To limit the effect of this risk patients were requested to choose the person who looked after them for interviewing when they were unable to take part.

Longitudinal methods also generate a plethora of data and can prove overwhelming. QRS Nvivo data management package was (QRS International Pty Ltd, 2010) helpful in storing and organising data and for keeping an audit trail for analysis. Other challenges faced in employing longitudinal qualitative methods in subsequent sections.

### **Participant recruitment, retention, and attrition**

Despite these difficulties noted above, recruitment was successful. Patients valued taking part in the study and appreciated having time to speak about issues they found difficult to bring up with doctors or nurses. Although there are ethical concerns regarding patients' increasing vulnerability, declining cognitive capacity, and the emotional burden of interviewing people with life-threatening illnesses, patients appreciated time to speak confidentially about their experiences which they found difficult to share with those closest to them (Gysels et al., 2008). Participants were also happy to take part knowing that their experience would be helpful to others.

However, some patients thought there was something to gain from taking part. For example, Njenga a 31-year-old male with NYHA IV heart failure thought that his participation would lead to financial assistance or subsidized treatment. These expectations were possibly drawn from other studies in this context that offer treatment (for example anti-retroviral therapy in HIV/AIDS studies) as part of their design. The effect of participants' expectations will be discussed further in the section on reciprocity.

Providing information sheets and consent forms in a language participants could understand improved chances of a participant deciding to take part. Participants appreciated the opportunity to make an informed decision as this respected their autonomy. Monthly phone calls were particularly helpful with retention. Most patients had a personal mobile phone or had access to one through their carer, friend or a neighbour. Patients appreciated regular

phone calls, as they felt valued that the study was more than just about generating data but about understanding their experiences and concerns.

Four participants dropped out and five died before the study period. It was hard to ascertain reasons for dropping out, as participants were untraceable through their phone numbers or those of their carers. Attrition should be expected in studies with patients with life-threatening illness. It reflects external validity and the selection of an appropriate sample representative of the population of interest (Preston et al., 2013).

### **Researching the vulnerable**

Flaskerud and Winslow (1998) define vulnerable populations as people who have an increased risk of unfavourable health outcomes such as premature mortality, morbidity and reduced quality of life. Socio-economic status further compounds vulnerability. Participants in this study were vulnerable on two fronts: they had a diagnosis of a life-threatening illness with poor health outcomes, and most were economically disadvantaged with few able to afford regular care.

Longitudinal methods are beneficial as they foster a trusting relationship to develop between the researchers and researched. A trusting relationship allows for the discussion of sensitive issues that may be difficult to speak about during an initial interview. While these methods were helpful in exploring patients' dynamic experience, I found that they challenged the researcher-participant relationship.

As the research relationship grew, patients would reveal more about themselves including personal problems. Patients shared challenges in affording treatment, paying house rent and school fees for their children.

Given the relationship I had developed with participants over time, it was hard to listen to them speak about these challenges and not respond.

Although qualitative methods endeavour to explore phenomena in its natural setting (Creswell, 2007), failing to answer to participants' pressing needs was likely to affect the relationship we had developed. Kenya lacks a social welfare service, and most people rely on their family, friends and their community to help with difficult financial situations. To help participants, I set up a small fund to support participants with pressing financial needs and help sustain relationships. The consequences of this are reviewed further in the section on reciprocity.

### **Home as place of interview**

In qualitative research, data collection takes place where the participant feels most comfortable (Liamputtong, 2006:66). In most cases, this is the home. In this study, most participants were comfortable with interviews taking place in their homes. However, male patients particularly those who were middle-aged and living alone, preferred to have interviews at a public venue (mostly at restaurants). One male participant who declined to take part was not keen on a home visit but asked if the interview could be done over the phone. In contrast, men who were married or lived with a female relative were more comfortable with interviews being conducted at home. The traditional household role of women in the context of most Kenyan communities includes welcoming visitors into a home. Although I presented myself as a researcher to participants, they viewed me as a social guest. Some participants would invite me to share a cup of tea or have lunch with them after an interview. Due to these traditional gender expectations, male

patients who lived alone may have felt unprepared to have interviews conducted at home.

### **Reciprocity**

Reciprocity involves a process of give and take where researcher and participant(s) share in the research process. It helps to balance hierarchy between the participants and researcher. Participants share their experiences while a researcher gives back to the participant to acknowledge their participation (Liamputtong, 2006:62). Reciprocity may take various forms including financial incentives, sharing research findings with participants or community service work (Dickson-Swift et al., 2008). In selecting an appropriate token to offer research participants, it is important to be aware of their expectations. For this study, patients were provided a grocery pack worth Ksh 500 (£4) at the end of each interview. In hindsight, most patients were more concerned about affording treatment. It was challenging to balance expectations regarding financial help for treatment and sustaining a trusting relationship to facilitate interviewing. By failing to address their pressing needs, participants may have viewed me as disinterested about their concerns. Future studies should account for participants' expectations in regards to reciprocity. Although financial compensation is a sensitive issue as it might be misunderstood as coercion, it may be appropriate for this context as it allows helps to maintain the trust needed for the researcher-participant relationship to support data generation.

## **Interviews with patients**

This study sought patients' perspectives on their experiences and interviewed carers when patients could no longer take part in the research due to declining health status or death before the end of the study period. Previous similar studies exploring the experience of living with advanced illness have used linked interviews from patients, carers and health professionals to generate evidence for improving services (Kimbell et al., 2013, Pinnock et al., 2011). Multiperspective approaches to interviewing are helpful for exploring relationship dynamics between patients and carers (formal and informal), exploring complementary and contradictory viewpoints, exploring individual experiences and generating evidence on how to integrate care (Kendall et al., 2009). An advantage of single interviews is that patients may feel comfortable speaking about sensitive matters especially relating to their carers. In the course of the study, a few patients spoke about the problems they had with close family members. Knowing that the study was focused on their perspective may have helped patients feel more comfortable about sharing their experiences.

## **Who is a carer?**

This study intended to conduct interviews with patients who were also invited to choose 'a person who takes care of you' to be interviewed when they could no longer take part in the study. Recruitment followed a stepwise approach beginning with patients and then followed by carers. This stepwise approach has been found to be helpful in recruiting carers who have information that would add value to the study (Kendall et al., 2009).

What was interesting from this Kenyan study was to observe who patients nominated as their carer. Most patients choose the family member who not



only knew about their experience but also helped in paying for the cost of care. For example, Cege a 45-year-old male nominated his cousin who lived beyond the 35km recruiting radius. When asked if there was someone else who lived closer he could nominate Cege mentioned that his cousin paid for all his medical bills and knew more about his illness than anyone else. Although Cege lived with his mother and siblings, he did not nominate them to take part in the study. Similarly, Jamo a 36 year chose a friend as his carer because he helped with paying his hospital bills.

These findings show different understandings of 'the person who takes care of you.' A carer may be the person most aware of a patient's experience or the person most involved in paying for their care. A carer with a more financial involvement may not be aware of a patient's day to day experiences and might lack information that would add value to a study. However, the fact that a patient has selected someone most involved with the financial aspect of their illness may point to what is most important to them.

### **Concluding remarks**

The aim of this chapter was to present a reflection of my experience conducting this research in Kenya. Several challenges were highlighted namely: obtaining local ethics approval in Kenya, changes in the organisation of health care in Kenya and how this affected data collection, issues regarding participant recruitment, retention, reciprocity, and place of interview. The opportunities of applying longitudinal methods in this setting were discussed. The findings presented in this chapter offer helpful insights for future research in this context.

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## **Appendix 1 Peer reviewed scoping review**

### **Statement of contribution**

KK (candidate) formulated the research question, conducted the search, extracted data and prepared the first draft of the manuscript. Permission to reproduce granted.

# What is known about heart failure in sub-Saharan Africa: a scoping review of the English literature

Kellen Kimani,<sup>1,2</sup> Elizabeth Namukwaya,<sup>2,3</sup> Liz Grant,<sup>4</sup> Scott A Murray<sup>5</sup>

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For numbered affiliations see end of article.

Correspondence to Dr Kellen Kimani, School of Public Health, University of Nairobi, P.O. Box 19676-00200, Nairobi, Kenya; K.N.Kimani@sms.ed.ac.uk

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## ABSTRACT

We systematically reviewed and summarised existing knowledge on heart failure in sub-Saharan Africa (SSA). We searched the following databases Web of Science, EMBASE, Ovid MEDLINE, PsychINFO, Global Health, CINAHL and African Journals Online using a combination of key words: heart failure or congestive heart failure or cardiac failure. We limited our search to studies conducted in SSA and articles published 2000–2014. Twenty-seven articles met our inclusion criteria and all were quantitative studies. Existing knowledge is focused on 3 key areas: (1) epidemiology of heart failure, (2) psychological burden of heart failure, and (3) patient knowledge and compliance to treatment. SSA would benefit from longitudinal qualitative research on the experience of living with heart failure.

## INTRODUCTION

In the past few years, the myth that chronic diseases are exclusive to wealthier western nations<sup>1</sup> has been overturned. Sub-Saharan Africa (SSA) is currently facing an unprecedented double burden of infectious and non-communicable diseases.<sup>2</sup> Better survival into adulthood especially with antiretroviral therapy alongside urbanisation and shifts in nutrition and lifestyles associated with economic development are contributing to an epidemiological transition across traditional infectious diseases to chronic conditions such as cancer, diabetes and cardiovascular diseases (CVDs).<sup>1,3</sup> The burden of infectious diseases still remains heavy; these pose a threat to public health despite the efforts to improve infectious disease control in this region. However, CVDs are increasingly being recognised as an additional major threat to public health.<sup>1,4</sup>

Heart failure can be defined as a clinical syndrome in which a structural or functional cardiac abnormality limits the

ability of the heart to deliver sufficient oxygen to meet metabolic demand. Often patients present with signs and symptoms of fluid and salt retention, especially during acute phases of the illness. Traditionally, heart failure has been described with reference to a normal or reduced left ventricular ejection fraction.<sup>5</sup> However, differences in aetiologies of heart failure and diagnostic tools, such as ultrasound in SSA and western countries, may broaden this description. Although significant progress has been made in the treatment of heart failure, the prognosis remains poor and worse when compared with common cancers.<sup>6</sup> Sudden death may also occur at any point along the illness trajectory making it difficult to determine when a patient has entered into the terminal phase of their illness.<sup>7</sup>

Globally, heart failure affects more than 26 million people, with the majority of patients living in Europe or North America. Although western nations bear a larger heart failure burden, low resource settings face higher mortality rates.<sup>8</sup> Weaker health systems, inequitable access to effective healthcare, and catastrophic out-of-pocket spending on health contribute to poorer outcomes. Specifically, countries in SSA have the lowest total global expenditure on heart failure (0.16–0.25%). Inadequately funded health systems are unable to comprehensively care for patients' needs and may drive households to sell assets or exhaust

savings to access healthcare.<sup>9</sup> Additionally, the reduction in income from work days lost may plunge households into vicious cycles of poverty. This poses significant challenges not only for achieving health goals, but also for social and economic development.

Despite the fact that lower income countries carry a disproportionate heart

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## Review

failure mortality burden, much of the existing research evidence originates from western nations.<sup>10</sup> As SSA tackles an emerging epidemic from chronic diseases, including heart failure, there is a need to map the nature and extent of existing literature and identify research gaps whose evidence may inform much needed policy and practice.

In view of this need, this scoping review aims to (1) systematically review and summarise existing knowledge on heart failure in SSA, and (2) identify research gaps and priorities for future research.

## METHODS

Scoping reviews or studies are gaining popularity as a method of examining research evidence.<sup>11</sup> These aim to map existing medical literature to: determine the breadth and depth of a research activity, summarise key research findings, identify gaps in literature for future studies and inform systematic reviews. Unlike systematic reviews, scoping studies may not aim to evaluate the quality of studies to be reviewed.<sup>12</sup>

Although there is no precise method for conducting a scoping review, Arksey and O'Malley<sup>12</sup> offer a substantive staged methodological approach to guide the process of undertaking a scoping study which includes (1) identifying a research question of interest, (2) identifying relevant studies, (3) selecting studies, (4) charting data, and (5) collating, summarising and reporting results. As demonstrated below, this review borrows on the Arksey and O'Malley<sup>12</sup> approach to review and explore the breadth and width of existing literature in this field.

### Stage 1: identifying research question

The research question to be addressed in this review is: 'What is known from existing literature about heart failure in SSA'.

### Stage 2: identifying relevant studies

We took the following step to identify relevant studies.

#### Developed a search strategy for electronic databases

We aimed to identify journal articles that addressed our research question. We searched the following electronic databases: Web of Science, EMBASE, Ovid MEDLINE, PsychINFO, Global Health, CINAHL and African Journals Online.

We used the combination of disease and study location-specific terms. Study location terms were informed by the World Bank classification of countries in SSA.<sup>13</sup> Search strategies were modified to suit each electronic database (table 1).

In addition, we broadened our search to include key journals, websites of relevant organisations, and reference lists from the articles we identified.

**Table 1** Electronic database search strategy

	OR	OR
AND	Disease terms	Study location terms
	Heart failure	Africa, sub Saharan Africa, Angola, Benin,
	Cardiac failure	Botswana, Burkina Faso, Burundi, Cabo
	Congestive cardiac	Verde, Cameroon, Central African Republic,
	failure	Chad, Comoros, Congo, Democratic Republic
		of Congo, Cote d'Ivoire, Eritrea, Ethiopia,
		Gabon, The Gambia, Ghana, Guinea,
		Guinea-Bissau, Kenya, Lesotho, Liberia,
		Madagascar, Malawi, Mali, Mauritania,
		Mauritius, Mozambique, Namibia, Niger,
		Nigeria, Rwanda, Sao Tome and Principe,
		Senegal, Seychelles, Sierra Leone, Somalia,
		South Africa, South Sudan, Sudan, Swaziland,
		Tanzania, Togo, Uganda, Zambia, Zimbabwe

### Stage 3: study selection

Our inclusion criteria which guided study selection were: original research or review papers focused on heart failure in SSA (or any of its constituent countries), articles published in English, and studies recruiting people 18 years and above. We excluded commentaries, editorials, case studies and papers focused on drug development or physiological processes. Abstracts with unavailable full-text versions were also excluded. Owing to limited resources, we restricted our search to articles published in 2000–2014.

### Stage 4: charting data

All data were charted on an Excel spread sheet according to the author, year of publication study location, aim(s) of the study, study methods, population and key findings. We summarised data in line with the central aim of each paper, for example, heart failure epidemiology, psychological burden, and patient knowledge and treatment compliance. We reserved the search to original articles only.

## RESULTS

Our search strategy resulted in 1709 citations. We identified 118 abstracts which we examined for relevance. Forty-eight articles met our inclusion criteria and were reviewed. Twenty-seven articles were original articles while the remainder (n=21) were review articles. We reviewed 27 full-text original articles (figure 1).

Of the 27 original articles identified, African countries were represented as follows: Nigeria (n=16), South Africa (n=3), Cameroon (n=2), Tanzania (n=1), Ghana (n=1), Kenya (n=1), Rwanda (n=1). Two articles reported the results of the nine-country survey.

All original full-text articles identified were quantitative studies seeking to determine the epidemiology of heart failure, psychological burden or level of knowledge and treatment compliance in specific African countries. Most articles reported the results of observational hospital studies examining the aetiology,

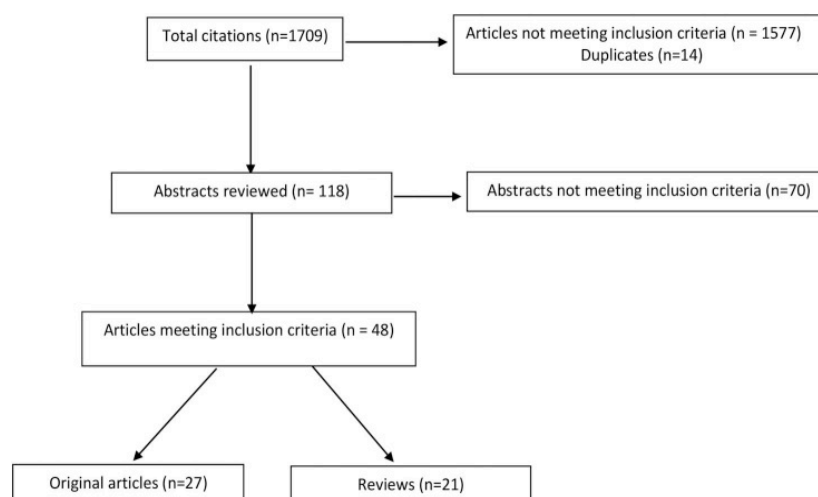


Figure 1 Literature identification and selection process.

characteristics, associated factors, and outcomes or knowledge level of patients diagnosed with heart failure.

Online supplementary table S2 summarises the articles retrieved.

In the following section, we outline three key topics we identified from our review of heart failure literature from SSA: epidemiology, psychological burden, patients' knowledge and compliance to treatment.

#### Epidemiology of heart failure

In SSA, the most common causes of heart failure are: hypertension (8–78%), cardiomyopathy (7.5–54%) and rheumatic heart disease (2.4–25%). Other causes include heart failure secondary to chronic obstructive pulmonary disease (4.4–27%), ischaemic heart disease (0.2–9%) and congenital heart disease (3%).<sup>14–23</sup>

In most facilities, heart failure accounts for 9.4–15% of all hospital admissions,<sup>15 20 24</sup> with length of stay ranging from 5 to 21 days.<sup>15 19</sup> Changes in life-style, metabolic abnormalities, exposure to environmental contaminants and viruses have been identified as risk factors for heart failure. Laabes et al<sup>25</sup> identified alcohol consumption, obesity and metabolic dysfunction as additional risk factors. Environmental factors, including poor kitchen ventilation and exposure to occupational dust, have been linked to cases of right-sided heart failure in Kenya.<sup>26</sup> Enteroviruses and HIV have been identified as risk factors for cardiomyopathy and right-sided heart failure, respectively.<sup>26 27</sup>

Comorbidity has been documented in people living with heart failure in SSA. In a Cameroon study, Dzudie et al<sup>28</sup> found renal impairment, chronic obstructive pulmonary disease, and gout as common comorbid conditions diagnosed in people living with heart failure. Comorbid psychiatric disorders, such as major depression, generalised anxiety and

schizophrenia, have also been identified and linked to poorer quality of life especially in people of younger age.<sup>29–31</sup> Coexisting conditions, such as cancer, HIV, chronic lung disease and poor kidney function, have been identified as prognosticators of mortality.<sup>32</sup>

#### Psychological distress

Using the hospital depression and anxiety scale, Ansa et al<sup>33</sup> evaluated the presence of depression and anxiety in 100 people living with heart failure in Nigeria. More than a third (39%) of patients had both depression and anxiety, while 16% and 13% reported having depression or anxiety, respectively. Similarly, Mbakwem and Aina<sup>34</sup> identified depression in nearly two-thirds of 122 admissions, and one-third of 82 outpatients with heart failure in Nigeria. Young people are more likely to experience psychological distress due to the challenges of adjusting and coping with illness.

#### Heart failure knowledge and compliance with treatment

Ruf et al's<sup>35</sup> study on the adherence, self-care and knowledge of 200 people with heart failure in South Africa found that people had poor knowledge of their medication and its side effects, with more than half unable to mention any side effect of their medication. Patients who reported having received health education regarding their condition had twice as high knowledge scores than those who did not receive education. Poorest compliance was reported for diuretics due to their side effects. Similar results were reported by Bhagat and Mazayi-Mupanemunda<sup>36</sup> study of 22 Zimbabwean patients living with heart failure. Half of the patients were unable to correctly recall their prescribed medication and one-third were non-compliant.



## DISCUSSION

## Summary of findings

Since 2000, research on heart failure in SSA has focused on determining disease epidemiology by exploring patients' psychological distress, level of knowledge and compliance to treatment. All the studies we identified employed quantitative research methods and therefore may point to an urgent need to quantify and characterise an emerging chronic disease epidemic previously considered to occur mainly in wealthier countries.

From the results of our scoping review, we noted limited research on the understanding of the lived experience of people with heart failure in SSA. While some attention has been given to patients' level of psychological distress, to the best of our knowledge, the holistic lived experience of people with heart failure in SSA is yet to be described.

A first-hand account of patients' experience of living with heart failure is necessary to explore their multidimensional needs and inform appropriate services. Previous studies have identified significant symptom burden, psychological and spiritual distress.<sup>37</sup> Patients also report poor understanding of their illness and the need for more information and better communication from health workers. Presently, no cure exists for heart failure and a patient-centred approach to care focused on improving symptom control, quality of life and offering psychosocial support might be beneficial to patients and families.<sup>37</sup> Additionally, primary and secondary prevention strategies aimed at early identification, treatment and control of common causes of heart failure, such as hypertension, should be encouraged.

In developed countries, research into understanding heart failure patients' lived experience has gained interest.<sup>37</sup> This research has the potential to identify patients' needs, priorities and preferences with the aim of informing quality care. The results of our scoping review reveal the leading causes of heart failure in SSA as hypertension, cardiomyopathy and rheumatic heart disease, with the illness occurring two decades earlier compared with western countries, such as the UK,<sup>38</sup> and with younger people experiencing significant distress. Additionally, patients are likely to present with advanced illness while those on treatment have poor knowledge of their medication which results in non-compliance. However, given significant contextual differences, it is uncertain whether results from research on the lived experiences of patients with heart failure in developed countries can be transferred to SSA. Cognisant of this emerging research gap, Namukwaya et al<sup>39</sup> present initial findings of their research on the experience of living with heart failure in Uganda. In their conference abstract, the authors identify significant physical, psychological and spiritual distress, presentation in later stages of illness, recurrent admissions, poor awareness of symptoms

and financial challenges. In a recent review of the palliative and supportive care needs for heart failure in SSA, Selman et al<sup>40</sup> argue that similar research is urgently needed to inform services that account for differences in epidemiological, cultural, socio-economic and health system contexts of SSA.

The growing burden of heart failure is likely to impose significant challenges on already weak health systems in SSA. Arguments have been posed whether current primary care services are prepared to support care for those living with chronic diseases, including heart failure.<sup>41</sup> An integrated approach placing patients at the centre of their care may benefit people with heart failure. This model of care has been shown to improve patients' health status as involved in their own care are likely to experience less anxiety, which has been linked to patients' functional status. Patient-centred care has also been shown to reduce hospital visits and financial costs of care,<sup>42</sup> which may further reduce the risk of catastrophic health expenditure.

Although patient-centred care offers significant benefit, several challenges exist in its delivery. Population-based research describing the burden of chronic diseases in SSA remains scarce and thus the need for services is poorly defined. Inadequate research expertise and funding limits the extent to which health-care services can be appropriately informed in order to meet changing needs.<sup>43</sup> Challenges in health financing, access to quality medicines and technology, and the availability of well-trained and well-compensated health work force also present significant barriers to the delivery of patient-centred approaches.<sup>40</sup>

## Limitations of our review

In our review, we aimed to evaluate the depth and breadth of heart failure research in SSA in recent years. While we attempted to summarise the evidence in this field, we did not assess articles for methodological quality. Unlike systematic reviews, scoping reviews may not aim at assessing the quality of articles selected for review. Second, by limiting our search to articles published in English, we may have omitted several articles. Third, most of the studies included in our review were hospital-based surveys, which may not be representative of the general population in SSA or its constituent countries. Lastly, two-thirds of the articles included in our review originate from Nigeria and these studies were conducted in hospitals offering specialised services to a predominantly urban population. After South Africa, Nigeria records the second highest spending on heart failure in SSA.<sup>9</sup> We advise caution when applying the results of this review to other settings in SSA serving a primarily rural population which might not be comparably resourced.

## Implications for research

In order to inform services based on person-centred needs, the lived experience of patients with heart



failure in SSA should be explored. To investigate this, qualitative research methods would be suitable as these allow for in-depth understanding of patients' needs and preferences.<sup>44</sup> Specifically, longitudinal qualitative research is appropriate for exploring individual experiences through time. Using this method, we can map patients' needs from diagnosis to death.<sup>44</sup> To respond to the WHO's recent resolution that all member states should integrate palliative care in the care of all conditions in all settings,<sup>45</sup> and the urgent need for culturally appropriate research on CVDs,<sup>43</sup> countries in SSA would greatly benefit from evidence on the lived experience of patients with heart failure in order to inform practice and policy that meets patients' changing needs.

## CONCLUSION

SSA is currently experiencing a rising burden of chronic diseases, including heart failure. People living with heart failure experience an unpredictable illness and require services that meet their changing needs. In order to develop appropriate care, it is imperative to generate evidence to inform policy and practice. So far, research into heart failure in SSA has focused mainly on describing the epidemiology, psychological burden or level of knowledge and treatment compliance in specific African countries. However, evidence on the lived experience of people with heart failure in SSA may offer deeper insights into their needs and preferences. Additionally, longitudinal qualitative research methods would allow for an in-depth understanding of patients' illness experience along the heart failure trajectory. To the best of our knowledge, this research is yet to be conducted in SSA. Countries in SSA would benefit from longitudinal qualitative research on the experience of living with heart failure in order to develop social and culturally sensitive services that cater to patients' needs.

## Author affiliations

<sup>1</sup>School of Public Health, University of Nairobi, Nairobi, Kenya

<sup>2</sup>Centre for Population Health Sciences, the Usher Institute, University of Edinburgh, Edinburgh, UK

<sup>3</sup>Makerere Palliative Care Unit, Department of Medicine, Makerere University, Kampala, Uganda

<sup>4</sup>Global Health Academy, University of Edinburgh, Edinburgh, UK

<sup>5</sup>Primary Palliative Care Research Group, The Usher Institute, University of Edinburgh, Edinburgh, UK

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## Appendix 2: Articles retrieved for scoping review of heart failure (HF)

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
Adebayo et al	2009	Nigeria	establish the frequency and characteristics of HF	Observational study Hospital based	117 cases: 86 women and 91 men; Controls 48 women and 42 men Mean age 52.3±16.64 years (cases) vs 52.1±11.84 years (control)	<ul style="list-style-type: none"> <li>• Leading cause - hypertension</li> </ul>
Adewuya A.O et al	2006	Nigeria	Estimate the prevalence and correlates of major depressive disorder (MDD) in patients with HF	Observational study Hospital based	42 women and 60 men Mean age 63 years	<ul style="list-style-type: none"> <li>• 60% diagnosed with hypertension</li> <li>• 28% with MDD</li> <li>• MDD associated with unemployment, advanced NYHA staging and younger age</li> </ul>
Amoah et al	2000	Ghana	To evaluate 572 patients with HF	Observational study Hospital based	260 women and 312 men	<ul style="list-style-type: none"> <li>• Hypertension is the leading cause</li> </ul>
Ansa et al	2008	Nigeria	To describe seasonal variation in admissions	Review of hospital records	242 women and 300 men Mean age 52±12.8 years	<ul style="list-style-type: none"> <li>• Accounted for 6.9% of admissions</li> <li>• More admissions in the wet season</li> </ul>

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
Ansa et al	2009	Nigeria	Determine frequency of psychological distress (anxiety and/.or depression) and its correlates in Nigerian patients with HF	Observational study Hospital based	45 women and 55 men	16% of patients had anxiety 13% had depression 39% had both anxiety and depression Younger patients had more psychological
Bhagat and Mazayi-Mupanemunda	2001	Zimbabwe	Determine patients' adherence to prescribed treatment ; Determine patients' recall of information regarding their medication.	Observational study Hospital based	22 patients (14 men and 8 women) Mean age 45±6 years	<ul style="list-style-type: none"> <li>• 27% (6 patients) did not adhere to treatment</li> <li>• 45% (10 patients) could not recall treatment regimen</li> </ul>
Bloomfield et al	2016	Kenya	Determine the association between atherosclerosis and HF	Observational study Hospital based	125 cases (Mean age 61±13) ; 191 controls (58±12)	<ul style="list-style-type: none"> <li>• Causes of HF: Dilated cardiomyopathy 20% ; ischemic heart disease 18% ; hypertension 10% ; valvular heart</li> </ul>

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
						disease 18% ; right sided heart failure 8.5%
Damasceno et al	2012	9 African countries	To describe the characteristics, treatment and outcomes of patients admitted with acute HF	Multicentre Observational study	511 women and 495 men Mena age 52.3 years	<ul style="list-style-type: none"> <li>• Leading causes are non-ischemic: hypertension (45%), rheumatic heart disease (14.3%) and ischemic heart disease (7.7%)</li> <li>• Mainly affects those of middle age</li> <li>• 180 day mortality 17.8% (95% CI 15.4%-20.6%)</li> </ul>
Dzudie eta al	2008	Cameroon	To determine the clinical characteristics of HF, related risk factors ad comorbidities among adults	Review of hospital records	140 patients diagnosed with chronic HF 54 women and 86bmen Mean age 54.9 years	<ul style="list-style-type: none"> <li>• 56% had atleast one co-morbidity</li> <li>• Leading co-morbidity: renal (24%), COPD (17.1%), gout (16.4%), anaemia (15.7%) and diabetes mellitus (13.5%)</li> </ul>

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
Familioni O.B et al	2007	Nigeria	To determine the pattern and outcome of acute HF in hospitalised patients and the parameters associated with mortality and survival	Observational study Hospital based	27 women and 55 men Mean age $57.6 \pm 15.9$	<ul style="list-style-type: none"> <li>• Hypertension most common cause of acute HF (43%)</li> <li>• Morality at 36 months - 67%</li> <li>• Younger age and high literacy level associated with better survival</li> </ul>
Karaye et al	2008	Nigeria	To determine the causes of HF among patients admitted to a n Nigerian tertiary medical centre ; to determine the prevalence of factors known to be associated with poor prognosis among these patients ; to	Cross-sectional Hospital based	35 women and 44 men Mean age $46.90 \pm 17.89$	<ul style="list-style-type: none"> <li>• Hypertension is the leading cause of HF</li> <li>• Left ventricle ejection fraction is the most significant prognostic factor</li> <li>• Cardiomyopathy leading cause of HF in women</li> </ul>

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
			compare the factors and causes by sex			
Kwan et al	2013	Rwanda	Describe a decentralized strategy for HF diagnosis and management and report the clinical epidemiology at district hospitals	Review of hospital records	134 women and 58 men Mean age 35 years	<ul style="list-style-type: none"> <li>• Leading causes of HF are non-ischemic: dilated cardiomyopathy (54%), rheumatic heart disease (25%), hypertension (8%)</li> <li>• Nearly half staged as NYHA III or IV</li> </ul>
Labees et al	2008	Nigeria	To describe the spectrum of established HF risk factors and clinical features	Observational-hospital based	32 male and 70 female	<ul style="list-style-type: none"> <li>• Common risk factors: hypertension, obesity, alcohol intake, hypercholesterolemia</li> </ul>
Lagat DK et al	2014	Kenya	To test the hypothesis that specific environmental	Case control study	31 cases (median age 65 years) and 56 (median age 48 years) controls	<ul style="list-style-type: none"> <li>• HIV positivity, occupational dust exposure and lower kitchen ventilation</li> </ul>

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
			exposures and comorbidities were associated with idiopathic right heart failure (IRHF) in women of western Kenya		All were women	associated with IRHF
Makubi A et al	2014	Tanzania	To determine the aetiology, clinical characteristics and mortality of HF in Tanzania.	Prospective observational study-hospital based	210 men and 217 women Mean age 55 years	<ul style="list-style-type: none"> <li>• Leading causes of HF are non-ischaemic ; Hypertension (45%) , cardiomyopathy (28%) , Rheumatic heart disease (12%), Ishaemic heart disease (9%)</li> <li>• Mortality linked to anaemia, pulmonary hypertension, hospital admission and lack of education</li> </ul>



Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
Mbakwem et al	2008	Nigeria	To determine the comorbid psychiatric disorders in people with HF	Observational study Hospital based	31 women and 27 men Mean age 51.2±13.8	<ul style="list-style-type: none"> <li>• 26% of patients diagnosed with psychiatric illness</li> <li>• Depression (12%) is leading cause of</li> </ul>
Mbakwem et al	2008	Nigeria	To evaluate the pattern of depression among hospitalized and stable HF patients	Observational-hospital based	Hospitalised were 47 women and 65 men (Mean age 49.05±16.28) Outpatients 44 women and 38 men (Mean age 53.95±15.53)	<ul style="list-style-type: none"> <li>• 67% inpatients diagnosed with depression</li> <li>• 30% of outpatients diagnosed with depression</li> </ul>
Ogah OS et al	2014	Nigeria	Determine the profile, clinical characteristics, and intrahospital outcomes of acute heart failure	Prospective observational study-hospital based	248 men and 204 women Mean age 56.6 ± 15.3 years	<ul style="list-style-type: none"> <li>• Leading causes of HF are non-ischemic ; Hypertension (78%) , dilated cardiomyopathy (7.5%), cor pulmonale (4.4%), pericardial heart disease (3.3%), rheumatic heart</li> </ul>

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
						<p>disease (2.4%) and ischaemic heart disease (0.4%)</p> <ul style="list-style-type: none"> <li>• Length of stay <math>11.4 \pm 9.1</math> days</li> <li>• 92% were de novo presentations</li> <li>• Deaths occurred in women and those of younger age</li> <li>• The mean overall length of hospital stay was <math>10.8 \pm 6.1</math> days (range 2 to 61 days; median 9 days).</li> </ul>
Ogah OS et al	2014	Nigeria	To determine six-month outcomes in 285 patients admitted with acute heart failure	Prospective observational - hospital based	150 men and 135 women Mean age $56.3 \pm 15.6$ years	<ul style="list-style-type: none"> <li>• 7.5% died in 180 days</li> <li>• 75% in NYHA III</li> <li>• Greatest mortality for those with pericardial disease</li> </ul>

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
Ogah OS et al	2014	Nigeria	To examine the rate and predictors of readmission in patients discharged after an episode of HF	Prospective observational - hospital based	138 men 124 women Mean age $56.1 \pm 15.4$ years	<ul style="list-style-type: none"> <li>• 12.2% readmitted in 6 months</li> <li>• worsening HF symptoms is leading cause for readmission</li> <li>• predictors of readmission include &gt;60 years, BMI &lt;19 kg/m<sup>2</sup>, valvular dysfunction</li> </ul>
Oji et al	2014	Nigeria	Determine the pattern of heart disease	Prospective observational	747 men and 768 women Mean age $49.0 \pm 13.7$	<ul style="list-style-type: none"> <li>• Leading cause of HF are non-ischaemic Hypertension 61%</li> <li>• 80% presented in NYHA III and IV</li> </ul>
Okonko et al	2013	Nigeria	To determine the role of enteroviruses in the etiology of hypertension, cardiomyopathy and	Observational study	52 men and 18 women	<ul style="list-style-type: none"> <li>• Echoviruses (50%), Coxsackieviruses-B5 (27.8%) and A9 (5.6%) isolated</li> </ul>

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
			hypertensive heart failure			
Ola et al	2006	Nigeria	To assess the relationship between depression and HRQoL.	Cross-sectional study	58 men and 42 women Mean age 63.2 years	<ul style="list-style-type: none"> <li>Nearly 30% diagnosed with MDD</li> <li>Depression associated with poor QoL</li> <li>QoL linked to younger age and duration of illness</li> </ul>
Onwuchekwa et al	2009	Nigeria	To determine the causes and mortality rate of congestive cardiac failure in the University of Port Harcourt Teaching Hospital (UPTH), south Nigeria	Review of hospital records	181 women and 241 males Mean age 54.4 ± 17.3 years	<ul style="list-style-type: none"> <li>Leading causes of HF are non-ischaemic : hypertension (56%) , cardiomyopathy (12.3%), rheumatic heart disease (4.3%) , ischaemic heart disease (0.2%) ;</li> <li>18 (4%) deaths recorded</li> </ul>

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
Sliwa et al	2013	9 African countries	Determine the prognostic factors of re-admission and death	cross - sectional multicentre observational survey	511 women and 495 men Mean age 52.3 years	<ul style="list-style-type: none"> <li>• Predicators of readmission: cancer, lung disease, fluid overload and deteriorating kidney function</li> <li>• Predicators of 180 day mortality : similar to predictors of readmission including anaemia and HIV disease</li> </ul>
Stewart S et al	2011	South Africa	To examine the characteristics and pathways to right sided HF	Observational study - hospital based	379 women and 318 males Mean age 52.0±18.8 years	<ul style="list-style-type: none"> <li>• Leading causes: Left sided heart disease(31%),primary lung disease (26%) and 20% pulmonary hypertension</li> </ul>

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
Stewart S et al	2008	South Africa	To describe the clinical characteristics of HF	Observational - hospital based	365 men and 479 women Mean age 55±16 years,	<ul style="list-style-type: none"> <li>Causes of HF - hypertension (33%), cardiomyopathy 28% , right HF (27%)</li> <li>Leading co morbidity - renal disease (25%)</li> </ul>
Tantchou et al	2011	Cameroon	To explore the occurrence, the aetiology and the management of congestive heart failure in the cardiac centre of the St. Elizabeth catholic general hospital	Observational study - hospital based	98 women and 264 men 42.5±18 years old	<ul style="list-style-type: none"> <li>Leading causes were non-ischaemic: valvular disease (35%), cardiomyopathies (32%), hypertension (15%), pericarditis (7%), chronic obstructive pulmonary disease (8%),congenital heart diseases (3%)</li> <li>44% presented in NYHA III and 7% in NYHA IV</li> </ul>

Author (s)	Year Published	Country	Aim	Study methods	Population	Key findings
Verena et al	2010	South Africa	To examine the pattern of treatment adherence, self-care behaviour and treatment knowledge	Observational study - hospital based	91 women and 109 men Mean age $56 \pm 14$ years	<ul style="list-style-type: none"> <li>• 71% patients adhered to treatment</li> <li>• More than half unable to mention medication side effects</li> <li>• Health education improved knowledge scores</li> </ul>

## Appendix 3: Patients interview topic guide

Main topic	Questions or prompts (English)	Questions or prompts (Kiswahili)	Issues to be explored
History of illness			
	Can you tell me about how your problem? When did you notice there was something wrong? When were you told you had a problem? How did you cope? Did you go to see a doctor?	Tafadhali nieleze juu ya tatizo lako? Ni lini uliona ulikuwa na shida? Ni lini uliambiwa ulikuwa na shida? Ulikabiliana na hii shida aje? Ulienda kuona daktari?	Patient's perceived diagnosis;  Main issues experienced (physical, psychosocial, spiritual,)  How patient copes with these issues
Current issues			
Physical	What are your main problems?  Have you had any physical problems?  How do your physical problems affect your daily life?	Je, matatizo yako makuu ni magani? Je, umekuwa na matatizo yoyote ya mwili? Matatizo haya yanaathiri maisha yako ya kila siku kwa njia ngani?	Physical Symptoms:  (breathlessness, fatigue, ankle swelling)
Psychological	How do you feel about yourself? What do you worry about?	Je, unajihisi aje? Je, unawasiwasi juu ya nini?	Psychological symptoms: anxiety and depression
Social	Has your illness affected how you relate with family and friends?	Ugonjwa wako umeathiri uhusiano na familia ama marafiki?	Social support networks and isolation



Spiritual	Have you thought why this is happening? What helps you cope? How is this affected by your illness? What is important to you in life? Do you think about the future?	Je, umefikirira kuwa nini mambo haya yanatendeka? Nini inakusaidia kukabiliana na ugonjwa huu?Imeathiri ugonjwa yako aje?Je, ni nini muhimu maishani yako?Je, unafikiria juu ya maisha yako siki zijao?	Beliefs and if they help in coping
Experience and expectation of care			
	What type of care are you receiving? Is this helpful? Would you like to change the care you are receiving? What would you change about the care you receive?	Je, unapokea huduma ya aina gani? Inasaidia? Ungependa kuibadilisha? Ni nini ungebadilisha?	Awareness of the type of care being received, What do they expect from care and what would they change
	How do you find talking to doctors/nurses? Do you get a chance to ask questions? Do you understand what they tell you?	Unaonaje kuzungumza nan a dakatari/muuguzi? Je, unapata nafasi ya kuuliza maswali? Unaelewa vile wanakueleza?	Communication relationship with health professionals, Ease of communication with health professionals

## Appendix 4: Carers interview topic guide

Main topic	Questions or prompts (English)	Questions or prompts (Kiswahili)	Issues to be explored
Current issues			
Physical	<p>What are X's main problems?</p> <p>Has X had any physical problems?</p> <p>How does X's physical problem affect his/her daily life?</p>	<p>Je, matatizo ya X makuu ni magani?</p> <p>Je, X amekuwa na matatizo yoyote ya mwili? Matatizo yake yanaathiri maisha yake ya kila siku kwa njia ngani?</p>	Physical Symptoms: (breathlessness, fatigue, ankle swelling)
Psychological	<p>How do you think X feels about his or himself? What do you think X worries about?</p>	<p>Je, unadhani X anajihisi aje? Je, anawasiwasi juu ya nini?</p>	Psychological symptoms: anxiety and depression
Social	<p>How has X's illness affected how he/she relates with family and friends?</p>	<p>Ugonjwa yake imeathiri uhusiano na familia ama marafiki?</p>	Social support networks and isolation
Spiritual	<p>Do you think X has thought why this is happening?</p> <p>What helps X cope? How has this affected their illness</p> <p>What do you think is important to X? Does X think about the future?</p>	<p>Je, unadhani X anafikiria kuwa nini mambo haya yanatendeka? Nini husaidia X kukabiliana na ugonjwa huu?Imeathiri ugonjwa yake aje?Je, ni ninimuhimu maishaniya X?Je, unadhani anafikiria juu ya maisha yake siki zijao?</p>	Beliefs and if they help in coping

Experience and Expectation of care			
	<p>What type of care is X receiving? Was it helpful? Would X like to change the care he/she is receiving? What would X change about the care he/she receives?</p>	<p>Je, X anapokea huduma ya aina gani? Inasaidia? Angependa kuibadilisha? Ni nini angebadilisha?</p>	<p>Awareness of the type of care being received,</p> <p>What do they expect from care and what would they change</p>
	<p>How did X find talking to doctors/nurses? Did or does X get a chance to ask questions?</p> <p>What was X told about his/her illness? Did X understand what they were told?</p>	<p>X anaonaje kuzungumza na dakatari/muuguzi? Je, anapata nafasi ya kuuliza maswali? Anaelewa vile wanamweleza?</p>	<p>Patient's view of the care they receive</p>

## Appendix 5: Patient sampling matrix

Participant number	Aetiology of heart failure	Sex	Age	Level of education
1		F	18-34	No education
2		F	18-34	Primary
3		F	18-34	Secondary
4		F	18-34	Tertiary
5		F	35-60	No education
6		F	35-60	Primary
7		F	35-60	Secondary
8		F	35-60	Tertiary
9		F	>60	Secondary
10		F	> 60	Tertiary
11		M	18-34	No education
12		M	18-34	Primary
13		M	18-34	Secondary
14		M	18-34	Tertiary
15		M	35-60	No education
16		M	35-60	Primary
17		M	35-60	Secondary
18		M	35-60	Tertiary
19		M	>60	Secondary
20		M	>60	Tertiary

### Note:

**Aetiology of heart failure:** to reflect the local epidemiology- 30% ;  
Rheumatic heart disease; 25% hypertension; 25% cardiomyopathy; 10%  
pericardial disease (from tuberculosis); 5% other

**Sex and level of education** mirrors local demographics from the Kenya  
National Bureau of Statistics and Kenya National Health and Demographic  
Survey (2008/2009 )

**Age distribution** is based on hospital surveys of heart failure admission

## **Appendix 6: Patient information sheet - English**

### **Experiences of people with heart problems in Kenya**

#### **Patient information sheet**

##### **Introduction**

This is an invitation for you to participate in a research study. Before you decide if you would like to take part, I would like to tell you more about the study and what it involves. Please take time to read this leaflet. You can ask me any question before deciding to participate. You may also discuss this study with someone else first.

##### **What is the purpose of this study?**

This study is part of a PhD research project to understand the experiences and expectations of people who have heart problems. I wish to learn about their life, how they live with their condition, the care that they receive and if they would like their care improved. I would also like to know how their experiences and expectations change over a period of 6 months. This will help health professionals understand what it is like to live with a heart problem and how they can improve care for those with this condition.

I will speak to 19 other people who have the same condition as you. I would also like to talk to the person who takes care of you

**Do I have to take part?**

No. The choice is up to you. It is OK for you to say no if you are not interested in taking part. You are free to withdraw from the study any time you wish.

**What will happen to me if I take part?**

I will contact you and arrange to talk to you at your home or at a place that is convenient and at a date and time that is suitable for you. I will speak with you for about 1 hour. It is your decision how much you would like to share.

If you allow, I would like to speak with you again in the future. I will contact you by phone call every month to see how you are doing and if you would still like to take part in the study, I will arrange for a second interview after 3 months and a third interview after 6 months.

During each interview, I will ask about your illness and the care you are receiving. If at any time you feel unwell to continue with the interviews, you may choose someone who looks after you and I will ask you if I can contact them and invite them for an interview as well. I will ask them the same questions I ask you so that I can learn more about your illness but from their perspective as well.

I will record the interviews because it is hard for me to write down all that you have said. Recording the interviews will help me note down all that you have told me. I will ensure that you are comfortable with this first. You can decide not to have the interview recorded at any time.

**Is there anything else you require from me?**

Yes. I would also like your permission to look at your medical records in the hospital. This will help me understand the care you are receiving.

**What are the potential benefits?**

There are no direct benefits for taking part in this study. However, the results of this study may be used to improve the care of people living with your condition. Hearing from you and other people living with the same illness will help me understand how care can be improved. People who have participated in similar studies have found it useful..

**Are there any risks?**

No. There are no expected risks and your choice to take part in this study will not interfere with your current treatment. Also, there are no arrangements for compensation if you decide to take part.

**Will my information be kept confidential?**

Yes. Your name and personal details will not be shared with anybody and will be stored securely. Any information you give will be confidential and no one will recognize you from any report from the study. Your name and personal details will be removed from any written material. I may quote you, but I will not use any information that might identify you.

**What will happen to the results of the study?**

The results will be written as a PhD report and will be published in academic journals. This will help health professionals understand what it is like to live with your condition and how their can improve care for you and others will a similar illness. . You will also be offered an information leaflet with the main findings at the end of this study.

**Who has organised the study?**

I have organised this study as part of my PhD studies at the University of Edinburgh. I am part of a research team at the University of Edinburgh that supervises my studies.

**Contact for further information**

If you have any questions or if you would like to discuss any part of the study you can contact Kellen Kimani at 0722673510 or the Kenyatta National Hospital/University of Nairobi- Ethics & Research Committee:

**Kenyatta National Hospital**

P.O Box 20723 - 00202

Tel: (254) 020 726300 EXT 44102, 44355

Email: [uonknh\\_erc@uonbi.ac.ke](mailto:uonknh_erc@uonbi.ac.ke)

**What happens next?**

If you accept, I will contact you in a few days and ask if you would like to take part in the study. You can also ask me any questions you might have. If you decide not to participate, it is OK for you to say NO.



## Appendix 7: Patient information sheet - Kiswahili

### Masumbuko ya wenye ugonjwa wa moyo nchini Kenya.

#### Utangulizi

Naomba maoni yako yawe kama sehemu yangu ya utafiti kuhusu aina ya maisha ambayo wenye ugonjwa wa moyo huishi . Kabla hujaamua kushiriki utafiti huu ikiwa ungependa , hebu nikufahamishe zaidi juu yake na yale yanayo husika. Tafadhali tafuta nafasi usome karatasi hii. Na kabla hujaamua kushiriki ,uko huru kuniuliza swali lolote, tena uko huru kujadaliana na mtu mwingine kuhusu utafiti huu.

#### Kusudi la utafati huu ni nini?

Ningependa kujua shida au masumbuko na matarajio ya huduma au msaada kwa wagonjwa wa moyo. Natami kuelewa kuhusu maisha yao na vile wanavyo ishi katika hali hiyo. Pia natamani kujua kuhusu huduma wanayo pewa na pia kama wangependa iboreshwe. Tena ningetaka ninjue mabadiliko na matarajio yako baada ya miezi sita. Utafati huu ni sehemu ya masomo ya PhD.

Nitaongea na watu 19 walio na hali kama hiyo uliyo nayo , na pia ningependa kuongea na mtu ambaye hukuhudumia.

#### Ni lazima nishiriki utafiti huu?

La. Wamuzi wa kushiriki ni wako. Ikiwa hutaki uko huru. Hata ukishiriki na utake kujiepusha nao wakati wowote, uko huru.

### **Itakuwa aje kwangu nikichangia?**

Nitapanga kuongea na wewe ukiwa kwako ama mahali, taraha na saa utakazo amua. Nitaongea nawe kwa muda ya saa moja. Itakuwa wamuzi wako kuchagua yale tutakayo jadiliana. Na ikiwa utanihurusu, ningependa kuongea nawe baadaye maishani. Nitakupigia simu kila mwezi ili nijue hali yako na pia kama ungependa kuendelea na utafiti huu. Kisha nitapanga mahojiano ya pili baada ya miezi mitatu na mahojiano ya tatu baada ya miezi sita. Katika kila mahojiano, nitakuuliza kuhusu ugonjwa na huduma ambayo umekuwa ukipokea. Ikiwa unaweza kuhisi uchungu wakati mmoja au mwingine hata ushindwe kuongea, unaweza kumpendekeza mtu ambaye hukushughulikia, nami nitaomba kama inawezekana nizungumze naye. Nitamuuliza maswali sawasawa na wewe ili nijue mengi kuhusu ugonjwa wako.

Na kwa kuwa ni vingumu kuandika mambo yote utakayo ongea, nitayanakili kwenye chombo cha kunasa sauti (recorder). Kunakili mahojiano yetu kutaniwezesha kuyashika yote utakayo niambia, nitahakikisha kwamba umeridhika kwanza. Pia wamuzi ni wako kusema la, ikiwa hutaki mahojiano yako yanakiliwe, na unaweza fanya hivyo wakati wowote. Baada ya mahojiano, nita yaandika yote yatakayo kuwa yamenakiliwa.

### **Kuna jambo lingine ungehitaji kwangu?**

Ndiyo. Naomba uniruhusu nisome rekodi zako zote za matibabu hospitilini. Kuzisoma rekodi hizo kutanisaidia kuelewa vile ambavyo wewe hushughulikiwa.

### **Kuna faida gani za kuonekana ?**

Hakuna faida kwa kushiriki utafiti huu. Lakini, matokeo yah utafiti huu utasaidia kuboresha huduma kwa watu walio katika hali sawa na wewe. Ujumbe kutoka kwako na watu wengine wenye ugonjwa kama wako zitaniwezesha kuelewa vile huduma inaweza kuboreshwa. Wale wamewahi shiriki utafiti huu wanajua manufaa yake,.

### **Kuna hadhari zozote?**

La. Hakuna hadhari zozote zinazo tarajiwa. Waamuzi wako wa kushiriki utafiti huu hautahitilafiana na matibabu yako unayo pokea sasa. Tena hakuna mpango wowote wa kukulipa kwa kuwa umeamua kuchangia utafiti huu.

### **Ujumbe wangu utafichwa?**

Naam. Jina na mambo yako binafsi hayatashirikishwa mtu mwingine. Kila neno utakalo niambia litafichwa kiasi ya kwamba hakuna mtu atakaye kutambua kutokana na yale utakayo kuwa umechangia kwenye utafiti huu. Tena , jina lako na mambo yako binafsi yatafutwa kwenye nakala zote ambapo zitakuwa zimeandikwa. Ikiwa nitakunukuu, lakini sitatumia maneno ambayo yatakutambulisha. Jumbe zote zitakazo kuwa kwenye mtambo au mashine ya kunasa sauti (recorder) na zile zilizo andikwa zitahifadhiwa salama na majina yote yatafutwa.

### **Matokeo ya utafiti huu ni ya nini?**

Matokeo ya utafiti huu yataandikwa kama majibu ya PhD na yatachapishwa magazetini kwa manufaa ya wasomi. Jambo hili litasaidia wahuduma wa afya kuelewa ugumu wa hali unayopitia na jinsi wanavyoweza kuboresha

huduma kwako na wengine walio na ugonjwa kama huo ulio nao. Pia utaelezewa matokeo ya utafiti huu baadaye.

**Nani aliye panga utafiti huu?**

Mimi ndimi niliye panga utafiti huu, kama sehemu ya elimu yangu ya PhD katika chuo kikuu cha Edinburgh (University of Edinburgh) ambacho husimamia utafiti wangu.

**Ukitaka ujumbe zaidi?**

Ukiwa na swali lolote ama ungependa kujadiliana sehemu yoyote ya utafiti huu, wasiliana na Kellen Kimani 0722673510 ama kamati ya maadili na utafiti (KNH/UON Ethics and Research Committee):

Hospitali ya kitaifa ya Kenyatta

S.L.P 20723 – 00202

Simu: (254) 020 726 300 EXT 44102,44355

Barua pepe: [uonknherc@uonbi.ac.ke](mailto:uonknherc@uonbi.ac.ke)

**Ni nini kitakacho fuata?**

Ukinikubalia nitawasiliana nawe baada ya siku chache ili nijue kama utachangia utafiti huu. Pia uko huru kuniuliza swali lolote ambalo pengine uko nalo. Na ukiwa umeamua kutoshiriki utafiti huu, uko huru.

## Appendix 8: Patient consent form – English

### Experiences of people with heart problems in Kenya

#### CONSENT FORM: Patient

I confirm that I have read and understood the information about the project, as provided in the information sheet	
I have been given the opportunity to ask questions about the projects and my participation	
I understand that my participation is voluntary and I can withdraw at any time without giving reasons and I will not be penalised for withdrawing	
I agree that if I have to withdraw from the study for any reason my data up to that point may be used in the results of the study	
I understand that the study will involve me in taking part in up to 3 interviews over 6 months and these interviews will be audio-recorded and kept securely and destroyed 10 years after the end of the study	
I give permission for the researcher to call once a month to see how I am doing	
I agree for the research team to review my medical records for the purpose of the study	
I give permission for the researcher to approach my carer to obtain views about my illness	
I give permission for the researcher to use anonymised quotes in publications	
I give permission for the researcher to use data in secondary analysis in the future	
I agree to take part in this study	

Please initial the boxes if you agree to each statement

_____	_____	_____
<i>Name of participant</i>	<i>Date</i>	<i>Signature</i>
_____	_____	_____
Name of researcher	Date	Signature

## Appendix 9: Patient consent form- Kiswahili

### Masumbuko ya wenye ugonjwa wa moyo nchini Kenya.

#### Fomu ya kibali : Mgonjwa

*Tafadhali weka saini kwenye masanduku kama umekubaliana na kila maelezo.*

Nimehakikisha kwamba nimesoma na kuelewa kuhusu mradi kulingana na maelezo yaliyoko kwenye karatasi ya ujumbe.	
Nimepewa nafasi ya kuuliza maswali kuhusu mradi na kushiriki kwangu.	
Ninaelewa kushiriki kwangu ni kwa kujitolea na ya kuwa ninaweza kujiondoa wakati wowote bila sababu wala sitatoshwa chochote kwa kujiondoa.	
Nimekubali kwamba ikiwa nitajiondoa kwenye utafiti kwa sababu yoyote, maoni yangu kufikia hapo yatatumiwa kama majibu ya utafiti.	
Ninaelewa kwamba utafiti huu utanihusisha katika mahojiano mara tatu kwa zaidi ya miezi sita. Nayo mahojiano yetu yatarekodiwa kwenye chombo cha kunasa sauti na kuhifadhiwa salama hadi miaka kumi yatakapofutiliwa mbali ukiwa mwisho wa utafiti huu.	
Nimemruhusu mtafiti kuwasiliana nami mara moja kwa mwezi ili ajue vile ninavyo endelea.	
Nimekubali kikundi cha utafiti kitazame rekodi zangu za matibabu kwa kusudi la utafiti.	
Nimeidhinisha mtafiti amfikie mwangalizi wangu ili wapate maoni kuhusu ugonjwa wangu.	
Nimemruhusu mtafiti kuchapisha maneno yangu kwa njia ambayo sitajulikana	
Nimemruhusu mtafiti kutumia maoni yangu katika uchunguzi wa pili baadaye maishani.	
Nimekubali kushiriki utafiti huu	

\_\_\_\_\_

*Jina la Mshiriki*

\_\_\_\_\_

*Tarehe*

\_\_\_\_\_

*Sahihi*

\_\_\_\_\_

*Jina la Mtafiti*

\_\_\_\_\_

*Tarehe*

\_\_\_\_\_

*Sahihi*

## Appendix 10: Patient recruitment form

Experiences of people with advanced heart failure in Kenya

### PATIENT RECRUITMENT FORM

Date.....

Name of patient.....

Date of Birth:.....

Gender.....

Level of education.....

Occupation.....

Address.....

Telephone number.....

### CLINICAL DETAILS

Cause of heart failure

.....  
.....

Treatment plan

.....  
.....

Other significant co morbidities, previous medical history or comments:

.....  
.....  
.....

Please contact Dr Kellen Kimani on 0722 - 673

## Appendix 11: Anonymised details of patients approached but decline to take part in the study

Participant number	Aetiology of heart failure	Age	Sex	Level of education
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				



## Appendix 12: Letter to nominated carer - English

Kellen Kimani

Centre for population Health Sciences

University of Edinburgh

Email: [K.N.Kimani@sms.ed.ac.uk](mailto:K.N.Kimani@sms.ed.ac.uk)

Tel: 0722673510

Dear .....(Chosen carer)

I am writing with regards to a research study: 'Experiences of people with heart problems in Kenya'. This study is part of a PhD research project to understand the experiences of people living with heart problems in Kenya and ways in which their care can be improved.

.....(participant/patient's name) has agreed to take part in this study and identified you as the person most involved with.....(his/her) care. As a result, I am writing to ask if you would be willing to be interviewed, face to face, in order that I may understand, from your perspective, .....(participant/patients's name) experience of living with their heart problem.

I have attached an information sheet that explains more about this study and a consent form, which you may sign if you wish to participate.

If you choose to participate, I will contact you again in order to arrange an interview.

Yours sincerely,

Kellen Kimani

PhD Researcher

## Appendix 13: Letter to nominated carer - Kiswahili

BARUA KWA MWANGALIZI MTEULE

Kellen Kimani

Chuo Kikuu cha  
Edinburgh

Baruapepe: K.N. [Kimani@sms.ed.ac.uk](mailto:Kimani@sms.ed.ac.uk)

Rununu: 0722 673 510

Kwa..... (Mwangalizi aliyechaguliwa)

Naandika barua hii kuhusu utafiti wa 'Masumbuko ya watu walio na matatizo ya moyo nchini Kenya'. Utafiti huu ni sehemu ya mradi wa PhD ili nielewe maisha na masumbuko ya wagonjwa wa moyo nchini Kenya na mbinu za kuboresha kushughulikiwa kwao.

.....(mshiriki/jina la mgonjwa) amekubali kushiriki utafiti huu na kukutambua kuwa wewe ndiwe mhusika mkuu wa uangalizi wake. Kwa hivyo, ninakuandikia nikuulize kama utakubali kuhojiwa uso kwa uso ili niweze kuelewa kutokana na maoni yako jinsi.....(mshiriki/jina la mgonjwa) anavyoishi na matatizo ya moyo.

Nimeunganisha barua hii na karatasi ya ujumbe inayo elezea utafiti huu zaidi pamoja na fomu ya kibali utakayoweka sahihi ukipenda kushiriki.

Ukichagua kushiriki, nitawasiliana nawe ili tupange mahojiano.

Wako mwaminifu,

Kellen Kimani

Mtafiti – **PhD**

## **Appendix 14: Carer information sheet – English**

### **Experiences of people with heart problems in Kenya**

#### **Carer information sheet**

##### **Introduction**

This is an invitation for you to participate in a research study. Before you decide if you would like to take part, I would like to tell you more about the study and what it involves. Please take time to read this leaflet. You can ask me any question before deciding to participate. You may also discuss this study with someone else first.

##### **What is the purpose of this study?**

This study is part of a PhD research project to understand the experiences and expectations of people who have heart problems. I wish to learn about their life, how they live with their condition, the care that they receive and if they would like their care improved. I would also like to know how their experiences and expectations change over a period of 6 months. This will help health professionals understand what it is like to live with a heart problem and how they can improve care for those with this condition.

I will speak to 19 other people, who like you, care for people with a similar condition.

**Do I have to take part?**

No. The choice is up to you. It is OK for you to say no if you are not interested in taking part. You are free to withdraw from the study at any time you wish.

**What will happen to me if I take part?**

I will contact you and arrange to talk to you at your home or at a place that is convenient, and at a date and time that is suitable for you, when the person you care for is feeling unwell or is unable to participate in the study. I will speak with you for about 1 hour. It is your decision how much you would like to share.

I will record the interviews because it is hard for me to write down all that you have said. Recording the interviews will help me note down all that you have told me. I will ensure that you are comfortable with this first. You can decide not to have the interview recorded at any time.

**What are the potential benefits?**

There is no direct benefits for taking part in this study. However, the results of this study will be used improve the care of people living with heart conditions. Hearing from you and other people caring for those with this condition will help me understand how care can be improved. People who have participated in similar studies have found it useful.

**Are there any risks**

No. There are no expected risks and your choice to take part in this study will not interfere with the treatment of the person you are caring for. Also, there are no arrangements for compensation if you decide to take part.

**Will my information be kept confidential?**

Yes. Your name and personal details will not be shared with anybody and will be stored securely. Any information you give will be confidential and no one will recognize you from any report from the study. Your name and personal details will be removed from any written material. I may quote you, but I will not use any information that might identify you

**What will happen to the results of the study?**

The results will be written as a PhD report and will be published in academic journals. This will help health professionals understand what it is like to live with a heart problem and how they can improve care for those with this condition. You will also be offered an information leaflet with the main findings at the end of this study.

**Who has organised the study?**

I have organised this study as part of my PhD studies at the University of Edinburgh. I am part of a research team at the University of Edinburgh that supervises my studies.

**Contact for further information**

If you have any questions or if you would like to discuss any part of the study you can contact Kellen Kimani at 0722673510 or the Kenyatta National Hospital/University of Nairobi- Ethics & Research Committee:

**Kenyatta National Hospital**

P.O Box 20723 - 00202

Tel: (254) 020 726300 EXT 44102, 44355

Email: [uonknh\\_erc@uonbi.ac.ke](mailto:uonknh_erc@uonbi.ac.ke)

**What happens next?**

If you accept, I will contact you in a few days and ask if you would like to take part in the study. You can also ask me any questions you might have. If you decide not to participate, it is OK for you to say NO.

## **Appendix 15: Carer information sheet - Kiswahili**

<b>Masumbuko Ya Watu Walio Na Matatizo Ya Moyo Inchini</b>
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### **Karatasi ya ujumbe wa mwangalizi**

#### **Utangulizi**

Ninakualika ushiriki utafiti. Kabla hujaamua kuchangia, hebu nikueleze zaidi kuhusu utafiti na yale yanayo uhusu. Tafadhali jipe nafasi uisome karatasi hii. . Na kabla hujaamaua kushiriki ,uko huru kuniuliza swali lolote, tena uko huru kujadaliana na mtu mwingine kuhusu utafiti huu.

#### **Kusudi la utafiti huu ni nini?**

Hii ni sehemu ya mradi wa utafiti wa PhD ili nielewe masumbuko na matarajio ya watu walio na matatizo ya moyo. Nataka nijue maisha yao na jinsi wanavyoishi katika hali yao, uangalizi wanaopewa na kama wangependa kuboreshewa uangalizi. Pia, ningependa kujua vile masumbuko na matarajio yao yatakavyo kuwa baada ya miezi sita. Jambo hili litawasaidia wahudumu wa afya kuelewa masumbuko ya watu walio na matatizo ya moyo na vile wanavyoweza kuboresha huduma kwa walio katika hali hii.

#### **Kwa nini nilichaguliwa?**

Ulichaguliwa kwa sababu unamhudumia mtu aliye lazwa hospitalini akiwa na matatizo ya moyo. Mtu huyu pia amekubali kushiriki utafiti huu na amependekeza tuwasiliane nawe ili nijue kama wewe pia ungependa kuchangia. Nitaongelea watu kumi na tisa (19) ambao kama wewe, huwasaidia watu walio na hali iyo hiyo.

### **Ni lazima nichangie?**

La. Chaguo ni lako. Uko huru kukataa ikiwa hujavutiwa kuchangia. Uko huru kujiondoa katika utafiti wakati wowote.

### **Itakuwa aje kwangu nikichangia?**

Nitaongea na wewe kupitia simu ukiwa kwako nyumbani ama mahali, tarehe na saa utakayo amua, wakati ambapo unaye shughulikia hajisiki vizuri ama hawezi kushiriki utafiti. Nitaongea nawe kwa takriban saa moja (one hour). Itakuwa wamuzi wako kuchagua yale tutakayo jadiliana.

Na kwa kuwa ni vingumu kuandika mambo yote utakayo ongea, nitayanakili kwenye chombo cha kunasa sauti (recorder). Kunakili mahojiano yetu kutaniwezesha kuyashika yote utakayo niambia , nitahakikisha kwamba umeridhika kwanza . Pia wamuzi ni wako kusema la, ikiwa hutaki mahojiano yako yanakiliwe, na unaweza fanya hivyo wakati wowote. Baada ya mahojiano, nita yaandika yote yatakayo kuwa yamenakiliwa

### **Kuna faida gani za kushiriki?**

Hakuna faida kwa kushiriki utafiti huu. Lakini matokeo ya utafiti huu utatumiwa kuboresha huduma kwa watu wanaoishi na hali hizi za moyo. Kusikia kutoka kwako na watu wengine ambao huwahudumia watu walio na hali hii kutanisaidia kuelewa vile wanavyoweza kuboreshewa huduma. Watu ambao wamewahi kushiriki utafiti kama huu wameona manufaa yake

**Kuna hatari zozote?**

La. Hakuna hatari zozote zinazo tarajiwa na kushiriki kwako katika utafiti huu hakutahitilafiana na matibabu ya mtu unaye angalia. Pia, hakuna mpango wowote wa kukulipa ikiwa utaamua kuchangia.



### **Je, ujumbe wangu utafichwa?**

Naam. Jina lako na mambo yako binafsi hayatashirikishwa mtu yeyote na yatahifadhiwa salama. Ujumbe wowote utakao toa utafichwa na hakuna mtu atakaye kutambua kupitia habari zozote katika utafiti. Jina lako na mambo yako binafsi yataondolewa kimaandiko na ikiwa nitakunukuu sitatumia ujumbe wowote ambao pengine ungekutambulisha.

### **Matokeo ya utafiti huu ni ya nini?**

Matokeo ya utafiti huu yataandikwa kama majibu ya PhD na yatachapishwa magazetini kwa manufaa ya wasomomi. Jambo hili litasaidia wahudumu wa afya kuelewa ugumu wa kuwa na ugonjwa wa moyo na jinsi vile wanavyoweza kuboresha huduma kwa wale walio na hali hii. . Pia utaelezewa matokeo ya utafiti huu baadaye.

### **Nani aliye panga utafiti huu?**

Mimi ndiye niliye panga utafiti huu ukiwa sehemu ya masomo yangu ya PhD katika chuo kikuu cha Edinburgh nikiwa mmoja wa watafiti katika chuo hiki ambacho ndicho husimamia masomo yangu.

### **Ukitaka ujumbe zaidi;**

Ukiwa na swali lolote ama ikiwa ungependa kujadiliana kuhusu sehemu yoyote ya utafiti huu, wasiliana na Kellen Kimani kupitia: 0722673510 ama kamati ya maadili na utafiti (KNH/UON Ethics and Research Committee)

Hospitali ya Kitaifa – Kenyatta

S.L.P 20723 – 00202

Simu: (+254) 020 726300 Ext. 44102, 44355

Barua pepe: [uonknh\\_erc@uonbi.ac.ke](mailto:uonknh_erc@uonbi.ac.ke)

### **Ni nini kitakacho fuata?**

Ukikubali, nitawasiliana nawe baada ya siku chache na nikuulize kama ungepeda kushiriki utafiti huu. Pia, unaweza kuniuliza swali ambalo pengine ungelikuwa nalo. Tena, ikiwa utaamua kutoshiriki, uko huru kufanya hivyo.

## Appendix 16: Carer consent form - English

### Experiences of people with heart problems in Kenya

#### CONSENT FORM: Carer

Please initial the boxes if you agree to each statement

I confirm that I have read and understood the information about the project, as provided in the information sheet	
I have been given the opportunity to ask questions about the project and my participation	
I understand that my participation is voluntary and I can withdraw at any time without giving reasons	
I understand that the study will involve me in taking part in an interview which will be audio-recorded and kept securely and destroyed 10 years after the end of the study	
I give permission for the researcher to use anonymised quotes in publications	
I give permission for the researcher to use data in secondary analysis in the future	
I agree to take part in this study	

---

Name of participant

---

Date

---

Signature

---

Researcher

---

Date

---

Signature

## Appendix 17: Carer consent form – Kiswahili

**Masumbuko ya wenye ugonjwa wa moyo nchini Kenya.**

### FOMU YA KIBALI: Mwangelizi

*Tafadhali weka sahihi kwenye masanduku kama umekubaliana na maelezo.*

Nimehakikisha kwamba nimesoma na kuelewa ujumbe kuhusu mradi kama ulivyo wasilishwa kwenye karatasi ya ujumbe.	
Nimepewa nafasi ya kuuliza maswali kuhusu mradi na kushiriki kwangu.	
Ninaelewa kwamba kushiriki kwangu ni kwa kujitolea na kwamba naweza kujiondoa wakati wowote bila kutoa sababu yoyote.	
Ninaelewa kwamba utafiti huu utanihusisha katika hojiano ambao itarekodiwa kwenye chombo cha kunasa sauti na kuhifadhiwa salama hadi miaka kumi yatakapofutuliwa mbali ukiwa mwisho wa utafiti huu.	
Nimemruhusu mtafiti kuchapisha maneno yangu kwa njia ambayo sitajulikana	
Nimemruhusu mtafiti kutumia maoni yangu katika uchunguzi wa pili baadaye maishani.	
Nimekubali kushiriki utafiti huu	

\_\_\_\_\_

**Jina la Mshiriki**

\_\_\_\_\_

**Tarehe**

\_\_\_\_\_

**Sahihi**

\_\_\_\_\_

**Mtafiti**

\_\_\_\_\_

**Tarehe**

\_\_\_\_\_

**Sahihi**

## **Appendix 18: Sample fieldnotes**

### **1<sup>st</sup> interview with Shiru**

**Date :** 4<sup>th</sup> December 2014

**Time:** 10am -12 noon

**Where:** at her home

The first thing I notice was how breathless she was. After speaking a couple of sentences she had to stop to catch her breath. At the hospital, she seemed eager to hear about the project. I answered her questions and we agreed that I contact her after a couple of days to see if she was still willing to participate. I followed up with a phone call to find out how she was doing. She asked I call back the following day. I phoned the following day and she willing to take part in the study. We scheduled a date and time for the interview that was convenient for her and gave me directions to her home.

On the day of the interview, Mwangi, a male colleague who was kind enough to accompany me picked me up and drove me to Shiru's. We got lost a couple of times and had to call Shiru twice to confirm directions. Friendly pedestrians were also kind to point us in the right direction. We finally arrived at Shiru's home at 9:45am.

She welcomed us into her home – a stoned house. In her compound there was a cow shed, a small biomass plant she was setting up, an outside bathroom, pit latrine and her farm where she was growing maize. I noticed two young boys playing outside. She later told me they were her grandchildren.

Before she started the interview, she insisted we have a cup of tea so that we can 'speak properly'. All along she was quite breathless but insisted on

making sure I was comfortable. Other than her grandchildren there were no other people in the house. (? Social support)

Shiru mentioned that she worked as a clerk in a government office. She had photos of her children and grand children hung on the wall (signs of possible social support). After having tea, we went through the information sheet and she signed the consent form.

We started the interview with Shiru talking about the history of her illness which was initially difficult to follow. I found myself asking her the same questions as way of trying to understand her history of illness. One of the things that stood out was the different hospitals she had visited. It seems like she was in search of a cure for her symptoms. Her drugs were not helping and she seemed frustrated. She struggles to make sense of her illness. Asking why her? Why this illness? She has thoughts of death but also relies on her faith. On one hand she is managing her illness by being compliant to treatment and on the other questioning God – a sort of tension between her reality and her faith.

Throughout the interview, Shiru seemed emotional. Her eyes teared most of the time. She held a white handkerchief in her hand to wipe away her tears. Once we started to speak about the future she became distressed and I had to stop the interview. I only restarted the tape recorder when she said it was okay for us to proceed.

She spoke about not knowing about her diagnosis, death feeling close but not knowing when it will happen. She mentioned what she had heard from people (her neighbours) about her condition: that all that was left was to die.

Despite being a communal society there is a sense of loneliness. She mentioned few friends, mainly from work, seek to find out if she is well. She

would prefer people were concerned to ask her how she is doing. Despite her illness, Shiru is still resilient. She is installing a biogas plant in her home and has renovated her house.

For her care, she wishes for more doctors at the hospital. The lines take too long and she has to wait for a long time to be seen. She would also like for doctors to take time to explain to the patient about their condition. She wonders if she will get better or if she will die, but she doesn't know how to bring this up.

The interview lasted 50 minutes. We ended the interview with Shiru asking whether she will ever get better. I tried answering her question by explaining that chronic diseases require long term care. I found it difficult to answer this question. After seeing her so distressed I wanted to give her a more helpful answer. I felt helpless telling her continue with her treatment yet being fully aware of her prognosis

Points noted:

- Main physical symptoms: breathlessness, fatigue, cough
- Visits to multiple facilities with each facility investigated her a fresh. Lack of continuum of care – services are disjointed. Patients bear the costs of duplicated investigations.
- Her own thoughts of death and those mentioned by others: There are people who are wishing her well and hoping she gets better but there are those who also talk about her dying. Socially she receives support but at the same time there are those who speak about her dying
- Isolation: mainly support from her mother. Children are far away from home. Church and friends are not as supportive as she would like
- Questioning: Why me? What have I done? But at the same time relies on her faith in God
- Thinking about the future causes distress

- Communication with health workers: she would like to know about her condition and prognosis. She is not sure how to start this conversation
- Resilience in the midst of illness : she is renovating her house and installing biogas



## Appendix 19: codes generated for first set of interviews

1. History of illness
  - a. How is illness identified
    - i. Symptoms
    - ii. Cant tell you how it started
2. Diagnosis
  - a. Visiting multiple facilities
  - b. getting to the hospital
  - c. restarting quest for diagnosis
  - d. past illness to make sense of present illness
  - e. How a diagnosis is made
3. Alternative therapies
4. How it all started
  - a. Acute episode
  - b. non specific symptoms pointing to chronic illness
  - c. Anaemia
5. uncertainty in the illness trajectory
6. No preexisting illness
7. symptoms not controlled
8. constant referrals
9. treatment is the end
10. Misdiagnosis
11. not convinced of diagnosis
12. disrupted clinic appointments
13. returning to normal
14. Decision making
  - a. When to seek care
    - i. severity of symptoms
  - b. Family role in decision making
  - c. When to seek care elsewhere
  - d. nearby clinics
    - i. resolving of symptoms
15. Role of carers
  - a. Family role
  - b. Proximity and coresidence
  - c. source of information
  - d. share the cost of care
16. Physical issues
  - a. Changes in daily activities
  - b. current physical main issues
  - c. Limits to daily life
  - d. consequences of illness as main physical issue
17. Maintaining identity or independence
  - a. provider

- b. Hygiene
  - c. Earn a daily living
- 18.
- 19. Psychological issues
  - a. role of religion
  - b. No need to worry
  - c. What has caused illness
  - d. Thoughts of dying
  - e. Most worried about
    - i. Money
    - ii. children
    - iii. Remaining independent
  - f. Loss of hope
  - g. sense of frustration
  - h. suicide
  - i. At peace
    - i. Anxiety and distress
  - j. Adjusting expectations
  - k. Peace
  - l. depression
  - m. uncertainty of the future
  - n. Acceptance
  - o. making sense of illness
  - p. being defeated
  - q. feeling about self
    - i. sadness
    - ii. slipping
  - r. feels limited by illness
  - s. where is this from
  - t. disappointment
  - u. feeling like a burden
  - v. hope to get better
- 20. Social issues
  - a. role of friends
    - i. Support
      - 1. financial
    - ii. source of information
    - iii. Church friends
  - b. How illness affects relationships with workmates
  - c. family as support
    - i. family offering financial support
    - ii. family offering support with everyday chores
  - d. How social relationships influence health seeking
  - e. Breakdown of relationships
  - f. not wanting to be a burden
  - g. how illness affects relationship with family
  - h. shrinking social support
  - i. isolation

- j. disappointment with relationships
- 21. Spiritual issues
  - a. religious fatalism and patient's illness perception
  - b. Belief that God works through doctors
  - c. Spirituality and healing
  - d. Why is this happening
    - i. family history
    - ii. Not complying to treatment
    - iii. stress
    - iv. I don't owe the world anything
  - e. accepting illness
  - f. belief it's a curse
  - g. state of limbo
  - h. belief in God in the midst of uncertainty
    - i. importance of prayer
  - i. life after death
  - j. questioning salvation and belief in God
  - k. choosing not to think about illness
  - l. unclean spirits
  - m. Health beliefs
    - i. Patient's perceptions
    - ii. Patient's knowledge
    - iii. Complying to health workers advice
      - 1. what is of immediate concern
      - 2. what has caused this illness
- 22. Information seeking behaviour
- 23. Patient provider relationship
  - a. Passive participation
  - b. patient responsibility
  - c. Active participation
- 24. Experience with care
  - a. poor care
  - b. care helpful
  - c. lack of information
  - d. not having enough money
  - e. want equipment in hospital
- 25. Universal health coverage
  - a. Lack of drugs
- 26. Treatment burden
- 27. Coping with illness
  - a. life as a gamble
  - b. Importance of prayer
  - c. belief in getting better
  - d. comparing yourself with others
  - e. church
  - f. sharing with friends
  - g. speaking about illness helps
  - h. believing there is a lot to be done

28. Thoughts about the future
29. What is important to you
  - a. remainig independent
  - b. God healing me
  - c. Love
  - d. To be healed
30. Expecatation of illness
  - a. adjusting expectations
31. Expectation of care
32. Patients questions and what they would like to know
33. Cost of making a diagnosis
34. Lack of information
  - a. Information on illness but not treatment
35. Communicable disease as cause of heart failure
36. Health seeking behaviuor
37. Influence of social relationships
38. cost of care
  - a. how government helps with cost of care
  - b. Family offering financial support
39. Advanced care planning
40. Accepting fate
41. Communicable disease as cause of heart failure
42. Consequences of illness as main physical issues
43. constant referrals
44. Coping with illness
45. life as a gamble
46. Importance of prayer
47. belief in getting better
48. comparing yourself with others
49. church
50. sharing with friends
51. speaking about illness helps
52. believing there is a lot to be done
53. Limits in the health system
54. Treatment received
55. Expectations from the study
56. faith in God in the midst of uncertainty
57. Accepting fate
58. poor communication
59. Barriers to communication
  - a. difficulties speaking to health workers
60. Differential diagnoses
61. Hygiene
62. What changes would you make to care
63. public percpetion of illness
64. Health systems challenges
65. Lack of understanding
66. Cost of illness

- a. Financial
  - b. relationships (business)
  - c. competing priorities
- 67. symptoms not controlled
  - 68. constant referrals
  - 69. Cost of drugs
  - 70. Nonadherence
  - 71. Consequences of illness as main physical issues
  - 72. What would you have liked to have known earlier
  - 73. Regret - information given but ignored
  - 74. If you got worse, what would you like to happen
    - a. Get treatment
  - 75. Self care
  - 76. trigger for admission
  - 77. Not aware of drugs they are taking

## Appendix 20: Initial thematic coding : themes and sub-themes

<b>1st INTERVIEW : DISRUPTIVE STAGE</b>  During this stage, patients experience radical changes in their physical, psychosocial, spiritual health	<b>2<sup>ND</sup> INTERVIEW: LIFE WITH HEART FAILURE</b>  This theme describes what life is like for patients after being diagnosed with heart failure	<b>3<sup>RD</sup> INTERVIEW: DYING WITH HEART FAILURE</b>  This theme describes the experience with dying with heart failure
<b>Theme 1: Diagnosing illness</b>  Identifying illness Misdiagnosis Seeking care	<b>Theme 1: Major concerns</b>  Persisting symptoms	<b>Theme 1: Major concerns</b>  Persisting symptoms - worsening Cost of care – changing costs? ? breaking family, cumulative - rising money burden – consequences ,
<b>Theme 2 Impact of illness</b>  Financial Social Psychological Spiritual/existential issues	<b>Theme 2 Impact of illness</b>  Financial costs (direct and indirect) Social Psychological Spiritual	<b>Theme 2: Impact of illness</b>  Psychological impact Anxiety, frustration, thoughts about death ,loss of independence Social impact Support; isolation , feeling like a burden
<b>Theme 3 Illness expectation</b>  Recovery No recovery	<b>Theme 3 Illness perceptions</b>  I don't have a heart problem This illness is for the rich Harmful lifestyle habits Its for the old	<b>Theme 3 Illness perceptions</b>  Normal illness Traditional belief Witchcraft, curses, ignoring cultural

	What if it is chronic?	customs  'Once you get this illness in your body, you can't tell it go
<b>Theme 4 Experience with care</b>  Awareness  Relationship with health professionals  Health care communication	<b>Theme 4 Coping mechanism</b>  Religious beliefs  Sharing with others  Comparing with others  Maintaining hope	Theme 4 Illness expectation  Recovery  Get the right diagnosis
<b>Theme 5 Expectation of care</b>  Therapeutic expectation  Cost expectations  Information expectations	<b>Theme 5 Illness expectations</b> <b>Healing</b>  Acute illness	<b>Theme 5: Thoughts about death</b>  Place of death - hospital  My time hasn't come yet  That is for God to decide  I've divided property for my children  'T'd still want treatment'
	<b>Theme 4 Experience with care</b>  Awareness  Relationship with health professionals  Health care communication	
	<b>Theme 5 Expectation of care</b>  Therapeutic expectation  Cost expectations  Information expectations	

## Appendix 21: Ethics approval – University of Edinburgh (CPHS ethics committee)



THE UNIVERSITY of EDINBURGH

CENTRE FOR POPULATION HEALTH SCIENCES

**Ethics Review Group**

Medical School

Teviot Place

Edinburgh EH8 9AG

Telephone 0131 650 3239

Fax 0131 650 6909

email: [cphs.ethics@ed.ac.uk](mailto:cphs.ethics@ed.ac.uk)

16 July 2014

Dear Dr Kimani

**Re: Quality of life: experiences and expectations of patients with advanced heart failure in Kenya**

Thank you for resubmitting your documentation with the amendments that were requested by the CPHS ethics committee. The amendments have been judged satisfactory. I am therefore pleased to be able to inform you that the above study have been granted ethical approval.

Please be aware that this ethical approval is in respect of the protocol and methods as described in the documents submitted to the committee (with amended documents superseding predecessors). If there is in the future *a change* to the study design/protocol/methods, you should check whether this means your level 2 application form needs to be revised, and submit to the committee (via me), any documents that have been revised (study materials/protocol/level 2 form), using tracked changes. You should make clear in your covering email whether:

- (i) you are requesting ethical review of a study amendment; or
- (ii) you are not sure whether such is needed and, in the first instance, would like the committee's opinion on whether a formal approval is needed of the amended design/methods.

Yours sincerely

Lesley McGoohan

Ethics Review Group Administrator

CPHS: <http://www.cphs.mvm.ed.ac.uk/>

Ethical Review Group: <http://www.cphs.mvm.ed.ac.uk/intra/research/ethicalReview.php> (staff & PGR students only)



## Appendix 22: Ethics approval KNH/UON ERC



UNIVERSITY OF NAIROBI  
COLLEGE OF HEALTH SCIENCES  
P O BOX 19676 Code 00202  
Telegrams: varsity  
(254-020) 2726300 Ext 44355



KNH/UON-ERC  
Email: [uonknh\\_erc@uonbi.ac.ke](mailto:uonknh_erc@uonbi.ac.ke)  
Website: [www.uonbi.ac.ke](http://www.uonbi.ac.ke)



KENYATTA NATIONAL HOSPITAL  
P O BOX 20723 Code 00202  
Tel: 726386-9  
Fax: 725272  
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/352

Link: [www.uonbi.ac.ke/activities/KNH/UoN](http://www.uonbi.ac.ke/activities/KNH/UoN)

21<sup>st</sup> October 2014

Dr. Kellen Kimani  
School of Public Health  
College of Health Sciences  
University of Nairobi

Dear Dr. Kimani

**RESEARCH PROPOSAL- QUALITY OF LIFE: EXPERIENCES AND EXPECTATIONS OF PATIENTS LIVING WITH ADVANCED HEART FAILURE IN KENYA** (P469/07/2014)

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and **approved** your above proposal. The approval periods are 21<sup>st</sup> October 2014 to 20<sup>th</sup> October 2015.

This approval is subject to compliance with the following requirements:

- Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.
- Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH/UoN ERC within 72 hours of notification.
- Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH/UoN ERC within 72 hours.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. *(Attach a comprehensive progress report to support the renewal)*.
- Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
- Submission of an executive summary report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

For more details consult the KNH/UoN ERC website [www.uonbi.ac.ke/activities/KNH/UoN](http://www.uonbi.ac.ke/activities/KNH/UoN).

Protect to discover


Yours sincerely

PROF. M.L. CHINDIA  
SECRETARY, KNH/UON-ERC

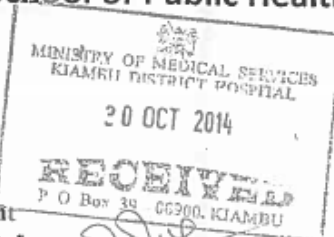
c.c. The Principal, College of Health Sciences, UoN  
The Deputy Director CS, KNH  
The Chair, KNH/UoN-ERC  
The Assistant Director, Health Information, KNH  
The Director, School of Public Health, UoN  
Supervisors: Dr. Elizabeth Grant, Prof. Scott Murray, Prof. Violet Kimani

## Appendix 23: Permission to collect data Kiambu District Hospital

(260)

  
**UNIVERSITY OF NAIROBI**  
College of Health Sciences  
School of Public Health

29<sup>th</sup> October 2014

  
MINISTRY OF MEDICAL SERVICES  
KIAMBU DISTRICT HOSPITAL  
20 OCT 2014  
RECEIVED  
P.O. Box 39 00900, KIAMBU

Medical Superintendent  
Kiambu District Hospital  
P.O.Box 39- 00900  
Kiambu  
Kenya

*Mid Sept 30/10/2014*  
*1 Noted Dr. Muriuki see before final approval*  
*Thurhe*

Dear Sir,


**RE: REQUEST TO COLLECT DATA AT KIAMBU DISTRICT HOSPITAL FOR RESEARCH PROJECT: QUALITY OF LIFE- EXPERIENCES AND EXPECTATIONS OF PATIENTS LIVING WITH ADVANCED HEART FAILURE IN KENYA**

I am writing to request for permission to collect data for the above mentioned research project.

This project is part of my PhD research which seeks to explore the lived experiences of heart failure patients with the aim of generating evidence to inform patient care.

For this project, data collection will consist of serial in-depth interviews with 20 patients with heart failure and review of their hospital records. Initial interviews will be conducted in the ward and subsequent interviews carried out at patients' home.

Please find attached my research protocol and ethics approval letter from the KNH/UON-Ethics & Research Committee (P469/07/2014) for your perusal.

Yours faithfully,  
  
Dr. Kellen Kimani

*30/10/2014*  
*Noted. Approve Applicant pa requisite fee*  
*A good study whose findings will assist as 12% of help to be necessary*  
*Noted Dr. Muriuki*  
*30<sup>th</sup>/10/2014*  
*Thurhe*

## **Appendix 24: Peer-reviewed publication and editorial**

### **1. Peer-reviewed publication**

#### **Statement of contibution**

The candidate (KNK) was the primary researcher. KNK collected all the data, conducted initial data analysis, and prepared the initial manuscript.  
Permission to reproduce granted

### **2. Peer-reviewed editorial**

KIMANI, K. N., NAMUKWAYA, E., GRANT, L. & MURRAY, S. A. (2017) Cancer and palliative care in Africa. *European Journal of Cancer Care*, 26 (1), e12655-n/a.

Available: <http://onlinelibrary.wiley.com/doi/10.1111/ecc.12655/epdf>

#### **Statement of contibution**

KNK reviewed the literature and prepared the first draft of the manuscript.  
Permission to reproduce granted.

# Spiritual issues of people living and dying with advanced heart failure in Kenya: a qualitative serial interview study

Kellen N Kimani,<sup>1</sup> Scott A Murray,<sup>2</sup> Liz Grant<sup>3</sup>

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<sup>1</sup>School of Public Health, University of Nairobi, Nairobi, Kenya

<sup>2</sup>Primary Palliative Care Research Group, The Usher Institute, University of Edinburgh, Edinburgh, UK

<sup>3</sup>Global Health Academy, University of Edinburgh, Edinburgh, UK

Correspondence to Dr

Kellen N Kimani;

[K.N.Kimani@sms.ed.ac.uk](mailto:K.N.Kimani@sms.ed.ac.uk)

## ABSTRACT

**Background:** Exploring patients' spiritual issues is vital for informing holistic care. The spiritual concerns of patients living and dying with advanced heart failure in sub-Saharan Africa remains unknown. Our aim was to describe spiritual issues in the context of the lived experiences of patients with heart failure in Kenya.

**Methods:** We purposively recruited 18 patients admitted with advanced heart failure at a rural district hospital in Kenya. We conducted serial in-depth interviews with patients at 0, 3 and 6 months after recruitment. We conducted bereavement interviews with their carers. Interviews were recorded, transcribed into English and analysed using a thematic approach, assisted by Nvivo software package.

**Results:** Patients expressed traditional and Christian spiritual beliefs in response to their illness. At diagnosis, some patients felt their illness had occurred because they had wronged God, while others felt betrayed by God. Some expressed comfort from God and optimism believing that God was in control and would heal their illness. During acute episodes patients questioned whether witchcraft or curses caused their illness. Younger patients experienced more spiritual distress. Although church fellowship generally offered spiritual and social support, some patients felt let down by the church which they perceived to favour those who offered more tithes.

**Conclusions:** This is the first study to explore the spiritual issues of people living with advanced heart failure in Kenya. Understanding patients' spiritual concerns is important for developing evidence-based patient-centred holistic care to promote multidimensional well-being.

## INTRODUCTION

The notion that spirituality influences how people experience disease is not new. Throughout human history, spirituality has strongly been associated with health and illness. For example, in prehistoric times, dis-eases were understood to be caused by super-natural forces and were treated by applying natural and spiritual practices.<sup>1</sup> In modern

## Key questions

What is already known about this topic?

- Spirituality influences how people experience illness.
- Diagnosis of a life-threatening illness may trigger existential angst.
- Spiritual distress may trigger physical and emotional distress and lead to increased health service use.

What are the new findings?

- This is the first longitudinal study to explore spiritual concerns of patients with heart failure in sub-Saharan Africa.
- Patients' spirituality offered comfort but was also a source of distress.
- Younger patients experience considerable spiritual distress.

Recommendations for policy

- This study highlights the need for patient-centred holistic care to identify spiritual concerns contributing to distress.
- Spiritual distress may lead to poorer health outcomes for patients.
- Holistic care may improve patients' wellbeing, reduce healthcare usage and curtail the vicious cycle of poverty associated with chronic dis-eases in this setting.

times, the importance of spirituality in health is evident from its inclusion in numerous clinical measures<sup>2</sup> including those that assess quality of life.<sup>3</sup> Furthermore, spirituality is also an important component of holistic approaches to care<sup>4</sup> including palliative care.<sup>5</sup>

Receiving a diagnosis of a life-threatening illness can be a traumatic experience. Questions such as *why is this happening?* or *why me?* often reveal existential angst as people attempt to make meaning of their diagnosis and the reality of death.<sup>6</sup> Previous studies on the experience of living with heart

failure (HF) conducted in the UK reveal that patients experience multidimensional distress throughout the illness trajectory. As physical symptoms deteriorate patients suffer a decline in psychosocial and spiritual well-being. Unpredictable acute episodes and the risk of sudden death mean that patients may be unprepared for worsening symptoms which may heighten their distress.<sup>7 8</sup> Poor communication from health professionals and a lack of understanding of their illness may add to their suffering.<sup>9 10</sup>

As patients struggle to find meaning they may rely on their spirituality to make sense of their experience. Westlake and Dracup<sup>11</sup> identified ways in which spirituality may help people with HF adjust to their illness. By searching for meaning in their experience, patients may regain hope and renewed optimism. Such positive spiritual responses have been associated with better health outcomes as patients experience fewer symptoms of depression,<sup>12</sup> enhanced quality of life<sup>13</sup> and better health practices<sup>14</sup> such as improved adherence to treatment.<sup>15</sup>

Sub-Saharan Africa (SSA) now faces a burgeoning epidemic from non-communicable diseases.<sup>16</sup> Although countries in North America and Europe may bear a greater disease burden, low-resource settings experience higher mortality rates. While the extent of the disease burden is yet to be quantified in SSA, hospital surveys estimate that HF accounts for 9–15% of admissions.<sup>17</sup> The unpredictable and long-term nature of these illnesses, together with its potential for significant psycho-social and spiritual distress, is likely to place a significant strain on the existing fragile health systems.<sup>16 18</sup>

In order to develop holistic services that can respond to patients' dynamic needs, it is vital to explore how their spirituality influences their illness experience. Unmet spiritual needs may lead more to physical, psychological and spiritual distress which results in more health service use.<sup>19</sup> Given the highly spiritual nature of communities in SSA and the considerable role of spirituality in well-being, it is crucial to explore how this influences the experience of living with HF in SSA. In this region, literature exists describing the role of spirituality for patients with chronic diseases such as cancer and HIV;<sup>20–22</sup> however, similar evidence from people living with HF remains scarce. This paper aims to fill this gap by reporting the spiritual issues of patients with HF in Kenya.

We acknowledge that spirituality is a complex phenomenon and definitions vary.<sup>23</sup> In this paper, we embrace a broad definition: "spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred".<sup>24</sup>

## METHODS

### Study design

We conducted a longitudinal qualitative study using serial in-depth interviews to explore patients' lived

multidimensional experiences. This methodology is useful for capturing dynamic needs and preferences along the course of illness. Given the sensitive nature of patients' accounts, longitudinal techniques allowed time for trusting relationships to develop between the participants and researchers facilitating the exploration of these sensitive issues.<sup>25 26</sup> Similar methods have been used to explore the spiritual concerns of patients living with cancer and non-malignant illnesses.<sup>7 19</sup>

Interviews were conducted at three monthly intervals up to a maximum of 6 months. However, this was flexible and dependent on a patient's health status or the occurrence of an event, such as a hospital admission triggering an earlier or later interview. KNK, a female Kenyan public health doctor conversant in the local vernacular as well as Kiswahili and English conducted the interviews. Interviews took place in hospital wards or at the patient's home and lasted 25–125 min. Patients were contacted on phone monthly to maintain contact and schedule subsequent interviews. Changes in their condition were recorded. Written consent was obtained before starting the first interview and confirmed verbally prior to subsequent interviews.

A topic guide was used to steer interviews. It explored patients' subjective physical, social, psychological and spiritual experiences including their experiences and expectations of care (see online supplementary file). Interviews were conducted in local language Kiswahili or English. Interviews were audio recorded in local language and transcribed into English by KNK with the assistance of an experienced transcriptionist. Field notes were written after each interview to record the observations made while interviewing.

### Methodological orientation

This research was underpinned by a critical realist theoretical orientation. Critical realism is a philosophy between relativist and objectivist theoretical perspectives. It claims to be a realist ontology and a constructivist epistemology. Reality is viewed as being external and independent but individually constructed. It underpins

several analytic approaches including thematic analysis.<sup>27–29</sup>

### Study participants

Patients were purposively recruited from a county hospital (previously a district hospital) serving a predominantly rural population in Kenya. Hospital doctors and nurses identified potential patient participants on the ward and informed them about the study. Patients were sampled to reflect the local epidemiology and sociodemographic characteristics of people with HF in this setting. This was guided by local statistics, hospital data and published literature.<sup>30</sup> We also asked patients to identify a carer for bereavement interviewing. In some cases we anticipated that patients would not wish to identify a carer. In such instances, we respected the patient's preference.

Forty patients admitted with a diagnosis of advanced HF classified as New York Heart Association Grade III/IV were found suitable by their clinician and approached for recruitment. Of these, 18 agreed to take part and 22 declined. Eighteen carers were also identified by patients for possible bereavement interviewing. We excluded patients with cognitive impairment, with a primary diagnosis of another advanced life-limiting illness (such as cancer) requiring most care, and those living beyond 35 km from the recruiting facility. Our sample size was informed by previous research in the experiences of patients with advanced HF in the UK suggesting that serial interviews with 20–25 participants would generate ample data to approach saturation and answer our research questions,<sup>31</sup> guidelines from ethics committees and resources available to successfully complete the study.<sup>32</sup>

### Analysis

Transcripts and field notes were analysed using the Braun and Clarke<sup>33</sup> approach to thematic analysis. The analysis included an initial data familiarisation phase followed by code generation to identify patterns. Codes were organised to form themes portraying participants' experiences with an ongoing review of themes to ensure data within themes were coherent and variations between themes were distinguishable. The analysis was iterative and occurred throughout the research process.<sup>34</sup> Regular multidisciplinary advisory group meetings (with LG, KNK, SAM) were held to review the emerging codes, themes and assess for data saturation. In addition, a research journal was kept to maintain reflexivity. Data management was assisted by qualitative package Nvivo. The COREQ checklist guided reporting.<sup>35</sup>

## RESULTS

A total of 18 patients (10 women; 8 men) took part in this study. Five patients died and four were untraceable by the end of the study. Two interviews were held with bereaved carers. All patients ascribed their religious affiliation as Christian and reported a belief in God with 15 regularly attending a church service. Attempts were made to recruit participants from other religious groups, but the predominance of Christianity in this community prevented this. All participants were Kenyans, the majority being Kikuyu.

Table 1 summarises participants.

Throughout their illness, patients experienced considerable multidimensional distress. Their physical decline was interrupted by periods of acute exacerbations. Physical symptoms such as breathlessness, fatigue, ankle swelling, exercise intolerance and insomnia were common. Most were poorly informed as they did not understand their diagnosis, treatment regimen or how to plan for the future. The cost of care was a significant burden for patients which at times resulted in significant

distress. Within this context spiritual issues were identified.

### Spiritual issues expressed at the time of diagnosis

Although most patients knew they had a 'heart problem', they were not aware of the significance of their diagnosis. They felt vulnerable as they were confronted by an unfamiliar illness. This often caused anxiety as patients questioned the origin of their illness. At this time, some patients derived comfort from their belief in an omniscient God.

Where is this illness from? We don't have this illness in our family....only God knows where it's from (Patient 6, woman, 60, 1st interview).

Other patients considered whether their illness was caused by a 'curse' from an estranged family member or a friend. These thoughts brought about feelings of victimisation particularly during periods of acute physical deterioration. However, once the symptoms had subsided with treatment these thoughts were ameliorated as patients felt confident that their improvement was proof that God had control over their illness.

Before I wonder whether if this (illness) is a curse because it (the illness) wasn't like this before.... but I stopped thinking about those things. It's God who knows and if it was a curse I would have died a while ago. It's only a disease and it will come to an end (Patient 12, woman, 19, 1st interview)

Most patients believed that their illness like other life events, were orchestrated by God. In their suffering, some patients felt it was inappropriate to express distress as this would reveal their distrust in God.

I don't worry about the concerns of this world... God does as he wills. I've decided never ask to ask God why he made me sick....he also takes those who are not ill. It's better to be ill as the Lord would wish. This body isn't mine. My body is his, my heart is his. God will do as he wills. The best you can do is be patient and wait on him (Patient 14, woman, 60, 1st interview)

For some patients diagnosis led to a questioning of belief in God.

The other concerns I have are religious....we all don't know where we are going to go. I've been a religious person but not that committed. Maybe I should believe in salvation....in case anything happens, I have nothing to lose....But if I choose not to believe I won't be sure of my fate. But with salvation I will have nothing to worry about (Participant 7, man, 50, 1st interview)

### Spiritual issues experienced during the time of treatment

For some, the second interviews revealed that once acute symptoms had subsided they felt confident in their hope for a full recovery. A reduction in



**Table 1** Participant characteristics

Patient number	Gender, Age	Aetiology of heart failure	NYHA class	Interviews			Duration in study (months)	Alive or dead at end of study	Bereavement interviews
				T1	T2	T3			
1	Female, 57	Hypertensive heart disease	III	P	P	P	6	Alive	
2	Female, 35	Hypertensive heart disease	IV	P	P	P&C	6	Alive	
3	Male, 65	Dilated cardiomyopathy	IV	P	P	P	6	Alive	
4	Male, 75	Right-sided heart failure (from COPD)	III	P&C	P&C	P&C	6	Alive	
5	Male, 31	Right-sided heart failure (from pulmonary fibrosis)	IV	P	P	P	6	Alive	
6	Female, 60	Hypertensive heart disease	IV	P&C	†		2	Dead	✓
7	Male, 50	Dilated cardiomyopathy	III	P	P	P	6	Alive	
8	Female, 50	Hypertensive heart disease	III	P	P&C	P	6	Alive	
9	Male, 38	Hypertensive heart disease	III	P	Untraceable		1	Not known	
10	Male, 45	Right-sided heart failure (from COPD)	IV	P	P	†	5	Dead	X—carer lived beyond 35 km from recruiting hospital
11	Female, 50	Hypertensive heart disease	III	P	P	P	6	Alive	
12	Female, 19	Extra pulmonary tuberculosis	IV	P	P	P	6	Alive	
13	Male, 60	Hypertensive heart disease	III	P&C	P	P	6	Alive	
14	Female, 60	Hypertensive heart disease	IV	P&C	†		1	Dead	✓
15	Female, 31	Dilated cardiomyopathy	III	P	Untraceable		1	Not known	
16	Female, 33	Hypertensive heart disease	III	P	P	P	6	Alive	
17	Female, 50	Hypertensive heart disease	III	P	P	Untraceable	5	Not known	
18	Male, 36	Right-sided heart failure (from COPD)	IV	P	Untraceable		1	Not known	

†Death.

C, Carer; COPD, chronic obstructive pulmonary disease; NYHA, New York Heart Association; P, Patient; T1, 1st interview; T2, 2nd interview; T3, 3rd interview.

breathlessness and symptoms such as fatigue and ankle swelling were interpreted as signs of their illness abating due to God's intervention. However, while hoping to recover, many patients also resigned their fate to the will of God. This acceptance was based on the belief that God controlled life and death. A few patients illustrated

this conviction by describing how death was not limited to those who are ill.

I don't worry...God knows how long I will live...I leave it to him. You know, someone in good health can die before someone who is ill (Patient 11, 50, woman, 2nd interview)

Patients whose symptoms persisted despite treatment expressed disappointment as they expected to recover. These feelings were compounded by those of guilt as they felt they had wronged God and that he had abandoned them in their time of need. In the absence of information, these feelings of guilt and disappointment exacerbated their distress

What have I done against you God? Haven't I lived my life as you expect me to? I have 'pressure', 'sugar' (diabetes), kidney and heart problems. Why should I be the only one to have these problems? Even after asking this, there is no answer. These illnesses are more than I can handle (Patient 1, 57, woman, 1st interview)

These feelings of guilt and disappointment were heightened especially in patients whose condition deteriorated requiring repeat admissions. In particular, younger patients experienced greater distress as they felt their illness had limited their ability to work and provide for their families. Additional challenges from unaffordable treatment and declining social support deepened their despair. One orphaned young man, who had made several attempts to end his life, told of his desire for God to end his suffering.

Instead of suffering and I'm not getting better, I'd pray to God to take me away. I don't have a job and I can't afford my drugs ...I pray to God to take away this problem...to shorten it rather than I continue to suffer (Patient 5, 31, man, 2nd interview)

And yet the powerfulness of the sense of God's ownership of life and the spiritual value of life enabled him to hold a counter narrative to his despair.

I still have hope because being alive everyday while in hospital is a blessing. A lot of things that happen in the hospital are shocking.... but when I see a new day, I thank God (Patient 5, 31, man, 2nd interview)

Feelings of deep despair led to patients simultaneously resigning their fate to God, and gained comfort in the belief that while their problems were insurmountable God was in control of life events. For some being alive in spite of severe illness meant that life still had purpose. There was a hopefulness in the peace and purpose they experienced in the face of deteriorating health.

God has a reason for everything. Even though it's a struggle to get to the hospital...I thank God for the help I receive (Patient 2, 35, woman, 2nd interview)

In these times of distress, the church was often viewed as a place of solace. The majority of patients described feeling a sense of tranquillity as they felt they were in the presence of God. Additionally, fellow church members offered support by sharing their experiences. However, a few patients described feeling abandoned by

the church as it failed to understand the issues they were going through.

Once church members found out I was sick they abandoned me. My senior pastor discouraged me to go to church. No one wants to be close to you when you have problems (Patient 16, woman, 33, 2nd interview)

Patients believed that illness created different dimensions of separation in some church communities. A few described discrimination and partisanship linked to well-being and prosperity.

Nowadays the church is not helpful. If you don't offer tithe as expected no one will know you. You see, I don't tithe all the time because I don't have money. I noticed that when someone tithes more they plan to visit them. But I've been admitted here for almost a month and no one has prayed for me. There is a lot of discrimination (Patient 2, woman, 35, 2nd interview)

### Spiritual issues as patients approached death

Most patients found it difficult to speak openly about death as they believed only God had authority over its timing.

There are those who are not sick but die from other causes. Yet, I'm ill and I'm still alive.....I take my life as is and pray to God (Patient 13, man, 60, 2nd interview)

For some it was easier to talk indirectly about death by sharing their future plans. One elderly man shared how he had planned for his children to inherit his property, a sign that he was willing to 'let go' and had come to terms with dying.

I have already made arrangements. Every child has a share of the land which they will get when I die (Patient 4, man, 75, 3rd interview)

Other patients responded by spending their last days in prayer asking God for forgiveness for past grievances. Their physical deterioration coupled with financial exhaustion from the cost of care and resultant tensions in social relationship appeared to aggravate patients' suffering. In this state of anxiety, patients felt let down by God and wondered if they had offended him.

Interviewer: Did she speak about why this was happening?

Carer: She would ask: 'Did I offend God?' She prayed a lot. She would pray day and night and ask God for forgiveness

(Carer for patient 14, woman, 60; bereavement interview)

Despite deteriorating health, some patients in their third interviews remained hopeful that a cure was still possible. They were hopeful that this would prove that



God had healed them. Patients were looking forward to sharing their experience with others to encourage and offer hope. For instance, 2 days prior to her death, a young female participant expressed her eagerness to share her illness journey as testimony of her belief in God's power to heal.

This illness is like a testimony. I'll tell people about my experience with this illness and let them know that it's God who sustains me. I was once in the intensive care unit and on oxygen and I got better... I will share my testimony (Patient 2, woman, 35, 3rd interview)

## DISCUSSION

Until recently, the multiple dimensions of the experiences of patients with HF in SSA were not described.<sup>17 36 37</sup> This paper illustrates ways in which spirituality influences the experiences of people with HF in Kenya. Spiritual distress was significant at diagnosis, during periods of acute deterioration and in the last days of life. This was often aggravated by the lack of information about their illness. Younger people were less able to cope with a loss of identity and independence. Patients rarely spoke about death as they felt that this was under God's authority although some had made plans for the future. Patients often relied on their belief in God to make meaning of their experience. Although this helped patients to cope, it at times contributed to their suffering as they struggled to reconcile their experience with a belief in a benevolent God. The church offered comfort for some but was also a source of distress.

Our results are comparable with similar longitudinal studies that show that patients experience multiple dimensions of distress.<sup>7 8</sup> In the UK, Murray *et al*<sup>8</sup> found that in people with HF spiritual well-being declines as physical symptoms deteriorate particularly during periods of acute exacerbations. Patients struggle to find meaning with thoughts of dying triggering existential angst as patients question divine indifference at the end of life.<sup>38</sup> People with HF may experience more pro-longed distress and uncertainty compared with those with cancer as their persistent and fluctuating physical symptoms creates uncertainty.<sup>39</sup>

Although these results are similar to those of our study, some findings are unique. We found that younger people experienced greater spiritual distress. Their expectation of remaining physically able to work as well as the societal pressures to provide for their families increased their anxiety. These patients have more difficulties in facing changes in their identity and increasing dependence.<sup>40</sup> Our findings reveal that people with HF in Kenya, draw on their spiritual beliefs to cope with their illness. These beliefs possibly stem from traditional religion in which God is regarded as orchestrator of life and death.<sup>41</sup> These beliefs are further reinforced by a Christian world view. Although these beliefs have been viewed as fatalistic,<sup>19</sup> they are a source of comfort<sup>42</sup> but

may also reflect a lack of information or a reflection of their deep hope for a cure.<sup>43</sup> Most of our sample expressed a Christian faith and turned to the church for solace. However, some patients felt rejected by the church's lack of support, especially those churches that appeared to assist more those who contributed most financially, exacerbated a sense of isolation among some.

## Implications for practice

Spiritual issues are often a source of unmet spiritual needs which has been found in the UK to increase physical and emotional distress and lead to greater health service use.<sup>19</sup> We found that patients relied on their personal resources such as upholding their spiritual beliefs and practices, praying and attending religious services.<sup>19</sup> While these resources offered comfort they were sometimes a source of distress.

As countries in SSA develop services for patients with chronic diseases, it is vital to acknowledge the significant role of spiritual issues in patients' illnesses. These issues have the potential to trigger deterioration in patients' symptoms, increase need for health services, escalate financial costs for families and contribute to a vicious cycle of poverty.<sup>44</sup> This presents further significant consequences for socioeconomic development as HF occurs predominantly in those who are economically active in this region.<sup>17</sup> In addition, spiritual support for those who are ill may be declining in the face of an emerging 'health and wealth' theology.<sup>45</sup>

Previous studies have suggested that a patient-centred approach aimed at meeting holistic needs may be beneficial to people with HF. This approach would aim to care for patients physical symptoms as well their psycho-social and spiritual needs. In addition to receiving medical care, this approach would allow patients to express their concerns, worries and existential anxieties and receive help in coping with and finding meaning in their experiences.<sup>19</sup> This may prevent their spiritual distress from contributing to greater service use and reduce the economic burden of care on families.

## Strength and limitations of the study

This is the first study to report the spiritual issues of patients living and dying of HF in Kenya. With a few exceptions past studies exploring the role of spirituality in health and illness have mostly relied on objective measurements.<sup>46</sup> In contrast, our longitudinal qualitative approach allows for dynamic and in-depth personal accounts of ways in which spirituality shapes patients' experiences. Patients were allowed to use their own words to explain how their beliefs not only helped them cope but at times added to their distress. The longitudinal nature of this study allowed us to build trusting relationships where patients felt at ease to disclose sensitive information.<sup>25 26</sup> The result, our approach was a rich and complex narrative in which patients described the role of spirituality in their illness experience. While

attempts were made to recruit participants from various sociodemographic, ethnic and religious groups living in Central Kenya, it is unknown to what extent these findings may be applicable in other settings.

## CONCLUSION

Spirituality for those living with HF in Kenya may be a source of comfort but also lead to distress. Patients' beliefs may mask underlying anxiety which may trigger multidimensional distress and lead to poorer health outcomes. This may increase health service use and plunge households into worsening poverty. A patient-centred holistic approach to care may be beneficial in identifying patients' spiritual concerns and offering support to improve their quality of care and quality of life.

Handling editor Seye Abimbola

Contributors KNK, SAM and LG developed and designed this study. KNK was the primary researcher. KNK collected all the data and conducted initial data analysis. All authors contributed to data interpretation. KNK prepared the initial manuscript and all authors contributed to its final version.

Funding This study was supported by the University of Nairobi PhD training programme.

Competing interests None declared.

Ethics approval Ethics approval was granted by the Kenyatta National Hospital/University of Nairobi Ethics and Research Committee (P469/07/2014) and the Ethics Review Group at the University of Edinburgh.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available.

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## Cancer and palliative care in Africa

**K.N. Kimani<sup>1</sup> | E. Namukwaya MBChB, M.Med, PhD, Palliative Care Physician<sup>2</sup> | L. Grant MA, PhD, Assistant Principal Global Health and Director of the Global Health Academy<sup>1,3</sup> | S.A. Murray Bachelor of Medicine, Doctor of Medicine, St Columba's Hospice Chair of Primary Palliative Care<sup>1</sup>**

<sup>1</sup>Primary Palliative Care Research Group, The Usher Institute, University of Edinburgh, Edinburgh, UK

<sup>2</sup>Department of Medicine, Makerere Palliative Care Unit, Makerere University, Kampala, Uganda

<sup>3</sup>Global Health Academy, University of Edinburgh, Edinburgh, UK

### Correspondence

Dr Kellen N Kimani, Primary Palliative Care Research Group, The Usher Institute, University of Edinburgh, Edinburgh, UK.

Email: K.N.Kimani@sms.ed.ac.uk

Cancer is a significant emerging public health concern in Sub-Saharan Africa (SSA). In 2012, there were 645 000 new cases of cancer on the subcontinent with nearly half a million deaths (Globocan, 2012). In the next 10 years, more than 20 million people worldwide will be diagnosed with cancer annually. The burden of cancer in SSA is also expected to escalate as 70% of global cancer deaths occur in middle- and low-income countries (Stewart & Wild, 2014).

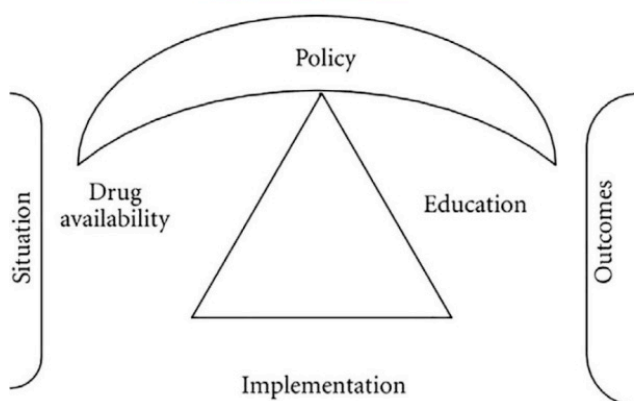
The predominant focus during the last 30 years on infectious diseases in SSA, and in particular HIV and AIDS, has led to the misconception that cancer is not a major problem for the region. However, two things are happening. As infectious disease control measures and treatment have improved survival into adulthood, more people are now living longer to accumulate exposure to risk factors commonly associated with cancer (Dalal et al., 2011). Improvements and changes in economies and the move towards increasingly urbanisation have seen a major increase in non-communicable disease (NCDs) risk factors. The adoption of unhealthy diets, unsafe use of alcohol and tobacco smoking coupled with decreased physical activity are spiralling the epidemic of NCDs (WHO, 2005).

Although infectious diseases are still the leading causes of death in SSA, the emergence of NCDs notably cancer presents a significant challenge for health systems. In this region, health systems are mainly orientated towards care for acute illness and maternal and child health. This contrasts with the needs of chronic diseases which require complex interventions to be sustained throughout the continuum of care (Samb et al., 2010). Where most people with cancer present to the health services with incurable disease, and where disease-modifying treatment is not accessible to most patients, palliative care offers a realistic public health approach to cancer care in this setting (World Health Organisation, 2002). While affirming life and considering death as part of a normal process, palliative care aims to improve the quality of life of patients and families facing life-threatening illness

through the early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems (World Health Organisation, 2004).

Across many developing countries and particularly in SSA countries, two forms of cancer predominate: (1) those associated with poverty and infectious diseases such as cervical cancer (Adewole, Benedet, Crain, & Follen, 2005) and (2) those linked to increasing wealth and unhealthy lifestyles such as lung cancer (Jemal et al., 2011). Regardless of the form of cancer, most patients present late when the disease is in its advanced stages and when anti-cancer therapy may not offer additional therapeutic benefit. In many parts of SSA, access to cancer screening and essential treatment services is poor. The region has the lowest global coverage of radiotherapy services with two thirds of its 277 radiotherapy machines located in only two countries: South Africa and Egypt (Abdel-Wahab et al., 2013). Similarly, access to chemotherapy is limited with only 5% patients receiving treatment (Wairagala, 2010). Health systems in SSA are challenged by this emerging burden of cancer. Fragile systems overburdened by infectious diseases, understaffing of health workers, inadequate diagnostic facilities and few facilities to offer specialised care impact the quality of care patients receive (Samb et al., 2010).

Several qualitative studies exploring the experience of living with incurable disease including cancer in SSA reveal that patients suffer from significant multidimensional distress. In Kenya, Grant, Murray, Grant, and Brown (2003) found that patients suffer with unrelieved pain which becomes increasingly intolerable as the disease advances and as patients approach their end of life. Most patients live restricted lives as their physical symptoms deteriorate and as negative feelings of hopelessness and despair dominate their lives. Although religious beliefs may offer some comfort, patients' thoughts are overwhelmed by concerns for how their families will cope (Murray, Grant, Grant, & Kendall, 2003). As the illness progresses, health care costs spiral. Patients are



**FIGURE 1** WHO public health strategy for palliative care. Source: Stjernsward et al. (2007)

unable to access their treatment and transportation costs become an additional financial burden. Increasing health care costs may lead families into poverty and strain much needed relationships (Murray et al., 2003; Ngutu & Nyamongo, 2015; World Health Organisation, 2005). Although families and communities are responsible for providing most care in SSA (de-Graft Aikins et al., 2010), urbanisation and migration threaten the breakdown of extended families and present new challenges for providing care to those who are chronically ill (Vento, 2013). The overwhelming unmet need for people in SSA is support for symptom control, especially pain control. This contrast greatly with patients in many economically developed countries where psychological and existential distress tend to predominate (Murray et al., 2003).

more than 26 African countries adopted the Kampala declaration and committed to providing leadership in implementing the 2014 World Health Assembly resolution on palliative care (ehopsice, 2016). This resolution supports the integration of palliative care to offer patient-centred services aimed at improving quality of life and ensuring dignified care for those with life-threatening illness such as cancer (World Health Assembly, 2014). Thirteen countries now include palliative care as part of their national cancer control plans (International Cancer Control Partnership, 2016) and six countries: Malawi, Mozambique, Rwanda, Swaziland, Tanzania and Zimbabwe have standalone palliative care policies (Harding, Luyirika, & Sleeman, 2016).

## 1 | PUBLIC HEALTH STRATEGY FOR PALLIATIVE CARE

Given the emerging burden of cancer in SSA and the challenges of providing essential care, the WHO public health strategy for palliative care offers an effective strategy for improving patients' quality of life by promoting equitable, accessible and cost-effective holistic care (Stjernsward, Foley, & Ferris, 2007). This approach aims to integrate palliative care by (1) developing national policies which prioritise the provision of palliative care; (2) ensuring adequate drug supply, distribution and prescription; (3) educating health care workers and the public to increase awareness, knowledge and skills of palliative care; and (4) implementing palliative care services in all levels of society with support from communities. Integration should be mindful of a country's health system and social-cultural context (Figure 1).

### 1.1 | Integrating palliative care in African countries

#### 1.1.1 | National policies

Significant progress has been made to integrate palliative care into country health systems. In August 2016, Ministers of Health from

#### 1.1.2 | Drug availability

According to Human Rights Watch report on the global state of pain, SSA has the lowest global consumption of opioid analgesics (Human Rights Watch, 2011). Morphine consumption stands at 0.391 mg per capita far below the world average of 6.24 mg per capita. Other opioid analgesics such as oxycodone, fentanyl and methadone are unavailable or also in short supply (Pain and Policy Studies Group, 2014). Challenges to morphine availability include poor drug distribution systems, cost of morphine and health professionals fear of legal repercussions for prescribing morphine (Human Rights Watch, 2011).

Despite these challenges, there are notable examples of countries making great strides to improve access to morphine. For instance, in 2004, the Ugandan government passed an amendment allowing nurses and clinical officers who have received training in palliative care to legally prescribe morphine. This has improved access to pain relief especially for patients living in rural communities (Jagwe & Merriman, 2007). Morphine is now on the Ugandan essential medicines list and is available to all patients at no cost. A dedicated country team also works to ensure consistent supply of morphine to all districts in the country. Furthermore, the Tropical Health Education Trust's (THET) project to support the integration of palliative care in four African countries has improved access to and consumption of morphine in 12 African hospitals. (<http://www.ed.ac.uk/files/atoms/>)

**Box 1 Case study of THET project**

**Methods.** A 3.5-year programme was implemented in 12 government hospitals, three each in Kenya, Rwanda, Uganda and Zambia. A fourfold approach of advocacy, staff training, service delivery strengthening and international and regional partnership working was utilised. A baseline needs assessment was undertaken, and 27 indicators were agreed to guide and evaluate the intervention.

**Findings.** Palliative care was integrated into all 12 hospital settings through concurrent interventions of these four approaches. Overall, 218 advocacy activities were undertaken and 4,153 community members attended awareness training. A total of 781 staff were equipped with the skills and resources to cascade palliative care through their hospitals and into the community. Patients identified for palliative care increased by a factor of 2.7. All 12 hospitals had oral morphine available and consumption increased by a factor of 2.4 over 2 years. Twenty-two UK mentors contributed 750 volunteer days to support colleagues in each hospital transfer knowledge and skills.

**Conclusions.** Integration of palliative care within different government health services in Africa can be achieved through advocacy at all levels from government to community, intensive and wide-ranging training, core services supported by resources including essential medicines, and an investment in partnerships between hospital, district and community.

Source: [http://www.ed.ac.uk/files/atoms/files/thet\\_ipcp\\_evaluation\\_report.pdf](http://www.ed.ac.uk/files/atoms/files/thet_ipcp_evaluation_report.pdf).

[files/thet\\_ipcp\\_evaluation\\_report.pdf](http://www.ed.ac.uk/files/atoms/files/thet_ipcp_evaluation_report.pdf)). This project has also improved delivery of palliative care services through advocacy, training and building local and international partnerships (Box 1).

palliative care associations, palliative care services in SSA are expanding (Ali, 2016; Mwangi–Powell, 2012).

**1.1.3 | Capacity building**

Education and training programmes are essential pillars for palliative care development in SSA. The Institute of Hospice and Palliative Care in Africa (an education unit of Hospice Africa Uganda) together with Makerere University offers diploma and bachelor degrees in palliative care and plans are underway for master's courses in palliative care (Hospice Africa Uganda, 2016). Palliative care is now included in undergraduate nursing and medical curricula in Botswana, Kenya, Malawi, South Africa, Uganda and Zambia. The Palliative Care Curriculum Toolkit developed by University of Makerere provides a resource for integrated teaching ([http://www.ed.ac.uk/files/atoms/files/final\\_curriculum\\_toolkit\\_-\\_oct\\_2016.pdf](http://www.ed.ac.uk/files/atoms/files/final_curriculum_toolkit_-_oct_2016.pdf)). The African Palliative Care Association, with partners, has developed several manuals and guide-lines to support the provision of palliative care in hospitals and in the community (<https://www.africanpalliativecare.org/resources-centre/>).

**1.1.4 | Implementing palliative care services**

As of 2010, 28 of 57 African countries were delivering palliative care (Wright, Wood, Lynch, & Clark, 2008), and by 2014, six countries namely Kenya, Malawi, Tanzania, Zambia, Zimbabwe and Uganda had integrated palliative care into country health systems (World Palliative Care Alliance, 2014). The Africa Palliative Care Association Palliative Outcome Scale (APCA POS) is now widely used for assessing patients' needs and evaluating the effectiveness and quality of palliative care (Harding et al., 2010). More recently, a link nurse programme at Mulago Hospital in Uganda has shown to be successful in improving the provision of palliative care services through the training and mentoring of nurses (Downing et al., 2016) and has been adapted in several hospitals in Africa. Through initiatives of APCA and country-level

**1.2 | Way forward**

Although significant progress has been achieved in making palliative care more accessible to patients with cancer in SSA, there is more to be done. Further efforts are required to mainstream palliative care services into country health systems. Service provision remains inconsistent and reliant on a few centres of excellence (Powell, Downing, Radbruch, Mwangi–Powell, & Harding, 2008) and a multi-sectorial collaborative approach in which palliative care is viewed as a responsibility for all and not just a select few is needed. Continuing government goodwill to support national palliative care policies and access to essential medicines will go a long way in improving access to quality care. Initiatives to support ongoing advocacy, education and training for health care staff and communities are essential for improving awareness, skills and knowledge to deliver effective palliative care (Bain, 2015; Mpanga Sebuyira, Mwangi–Powell, Pereira, & Spence, 2003). Service provision should be seamless and accessible to patients when needed. The World Health Organisation manual on planning and implementing palliative care services offers guidelines (11 Ps of integration) for successful palliative care integration starting at the district level (World Health Organisation, 2016). These should be underpinned by a strong research evidence base to guide policy and practice (Harding et al., 2013).

**2 | CONCLUSION**

As cancer emerges from the shadows of infectious diseases in SSA, a public health strategy to meet the holistic needs of people diagnosed with cancer can learn much from recent palliative care initiatives as most cancer patients present with advanced disease. Palliative care offers a realistic approach to equitable, accessible and cost-effective



interventions. This strategy should be supported as cancer prevention and treatment initiatives continue to develop.

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## Appendix 25: Conference presentations

1. May 2017: Oral Presentation, European Association for Palliative Care: "I find them so secretive' Information needs of patients living and dying of advanced heart failure in Kenya: a qualitative serial interview study"
2. January 2017: Oral Presentation, National Conference of Scottish Departments of General Practice (NADEGS): 'Living and dying of heart failure in Kenya: a qualitative serial interview study'
3. September 2016: Oral Presentation, Strathcarron Hospice Annual Conference: 'Living and Dying with Advanced Heart Failure in Kenya: a qualitative serial interview study' **Award: Best Oral Presentation**
4. September 2016: Oral Presentation, African Studies Association of the United Kingdom, University of Cambridge: 'Faith Dimensions of Patients Living with Advanced Heart Failure in Kenya'
5. August 2016: Oral Presentation, 5<sup>th</sup> International African Palliative Care Conference: 'We speak but it's superficial' Patients perspectives of doctor-patient communication: a serial qualitative interview study of patients' living with advanced heart failure in Kenya
6. March 2016: Oral Presentation, 11<sup>th</sup> Palliative Care Congress: 'Experiences and Expectations of Patients Living with Advanced Heart Failure in Kenya'



## **Appendix 26: Published paper reported in Kenyan press**

Daily Nation (2017) 'Dear Lord, why me? God on the firing line of heart patients.' Published 10<sup>th</sup> January 2017. Available:

<http://www.nation.co.ke/health/-God-on-the-firing-line-of-heart-patients/3476990-3511974-11pss2v/>. Last accessed 26 Apr 2017

This newspaper article reports the findings of the following research paper:

KIMANI, K. N., MURRAY, S. A. & GRANT, L. (2016) Spiritual issues of people living and dying with advanced heart failure in Kenya: a qualitative serial interview study. *BMJ Global Health*, 1 (3).

## **Appendix 27: Courses in qualitative research undertaken during PhD studies**

### **Qualitative Research Methods**

- Conducting Qualitative Research
- Qualitative Research in Health
- Reflexivity in Qualitative Research
- Sociology of Health and Illness

### **Qualitative Data Management**

- Introduction to Nvivo
- Nvivo: Beyond the Basics